

CARER POSITIONING IN SUPPORTING SOMEONE LIVING WITH CANCER AND DEMENTIA: A NARRATIVE APPROACH

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CARER POSITIONING IN SUPPORTING SOMEONE LIVING WITH CANCER AND DEMENTIA: A NARRATIVE APPROACH

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Abstract

Background

Evidence suggest that for people living with cancer and dementia the exploration of memory loss is superficially based upon patient or carer disclosure. Patients tend to underplay the importance and extent of memory problems in cancer consultations and staff found assessment challenging, avoiding exploring memory without an obvious therapeutic gain. Compared to cancer patients without dementia, people treated for cancer with pre-existing dementia are diagnosed at a later or unknown stage, receiving less treatment with more treatment complications and poorer survival. This highlights the challenge for carers in advocating and negotiating treatment choices with their relative.

Aim:

To examine the challenges of informal carers supporting someone with cancer and dementia within the United Kingdom

Methods:

In depth interviews were conducted with 7 informal carers using a narrative approach to examine the construction of their experiences. Recruitment took place at a Psycho-oncology unit at a tertiary cancer centre in the north west of England between July 2014-March 2015. Two participants were recruited external to the NHS through snowballing techniques. Both NHS and University ethical approval was obtained.

Results:

The findings demonstrate how informal carers navigate a path through complex cancer treatments and support their relative. A cancer diagnosis often requires multiple treatment visits to an oncology centre and this can be challenging for carers. They find that they need to co-ordinate and manage both health professionals and their care recipient(s) in terms of getting access to appropriate services and support. This process can be particularly challenging in the presence of a cognitive impairment that often demands effective communication with different agencies. Carers frequently experienced multiple challenges include dealing with the stigma that is characteristic of the dementia experience and the added complexity of negotiating this within a cancer care context. Issues of decision-making, best interests and quality of life were also of central concern for carers.

Conclusions:

Carers within this particular context face complex challenges that are not necessarily obvious and appear under reported. Their role is often rendered invisible by the nature of the care recipients' condition. We suggest health professionals need to respond to and support carers in different ways that do not stigmatise and hence discriminate against them.

Key words:

Cancer, carers, dementia, narrative

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To my critical friends for challenging and moving my thinking on throughout this journey (you know who you are).

Abbreviations

ACP	Advanced Care Planning
AD	Alzheimer's Disease
DH	Department of Health
DLB	Dementia with Lewy Bodies
GP	General Practitioner
MMSE	Mini-Mental State Examination
NHS	National Health Service
SoC	Sense of Coherence
SMI	Severe Mental Illness
VaD	Vascular Dementia

Chapter 1

Introduction to the study

1.1 Introduction

This chapter will explore my rationale for examining this topic area and how my previous experience has led me to undertake this work. I will discuss the background to the subject area, giving a context generated from policy drivers within cancer and dementia care within the United Kingdom. I will also explore carer identity since this is a contested term within the literature and will further describe the definition of carer that I have used within this thesis (1.4). I will further identify my research aims and given an overview of the structure of this thesis.

1.2 Background

This thesis was developed from previous work I conducted in examining the information needs of vulnerable people with cancer (those with mental health needs, learning disabilities and dementia). The project was challenged by difficulties in accessing these patients and overcoming the reluctance of gatekeepers to initially approach potential participants. These challenges were further examined (Witham et al 2015) and suggested that any future research would require a more proactive engagement with gatekeepers to identify and recruit participants. We managed to conduct focus groups with health professionals (Witham et al 2014) and the findings are presented in the subsequent literature review for this thesis. These data indicated the difficulties of carers of people with dementia in being included or consulted by health professionals when supporting their

relative/friend with dementia who is undergoing cancer treatment. I have a research interest in carer involvement within cancer, having previously been involved with research projects examining information needs of carers of women with breast cancer (Beaver and Witham 2007). My own experience of nursing within an oncology setting both as a ward-based nurse and then as a clinical nurse specialist has led to an acute awareness of the role of relatives/friends in supporting people living with cancer. As a specialist nurse I have been involved with multidisciplinary teams (MDT) examining treatment pathways but at no point has the wider network of patient care and/or support been actively sought or encouraged. The wider 'care triad' (Adams and Gardiner 2005) of patient, supporter or carer and health professional was often absent from the clinical environment. This individualism appeared to have consequences and at times led to patient isolation and a poor professional grasp of the wider community of support vital for recovery. It reminded me of the work of Frank (1995) in his telling of the stories of those experiencing cancer care. In spite of the good intention of healthcare staff he was witness to a series of difficult, tragic and painful stories of cancer care and from this proposed three narratives (or genres) prevalent within contemporary healthcare: the restitution, chaos and quest narratives. Frank's (1995) work had strong resonance with my own experience of cancer care where restitution was the main health professional focus and begins with the plot "yesterday I was well, today I am sick but tomorrow I'll be well again". The therapeutic goal was to achieve cure and maintain quality of life at a level equivalent to pre-diagnosis. This restitution was a plot shared with patients; the doubts, setbacks and uncertainties of a life-threatening condition are silenced in the call to restitution. Treatment was the main goal; even if this appeared futile, it also continued in the face of chronic co-morbidities that reduced quality of life further. The chaos narrative often appeared to stem from the perceived hopelessness of an unmanageable scenario that

no redemptive plot can be generated, sustained or imagined. Patients with challenging social situations and those with other co-morbidities such as dementia presented a fractured and unresolved narrative that was not readily fixed or managed through biomedical interventions. In my experience, this unnerved my nursing and medical colleagues and challenged the common attempts to impose a quest narrative, the “meaning making” surrounding this biographical disruption that cancer can cause. Those living with cancer and dementia and their carers could not examine the journey in terms of new beginnings, of creating a more meaningful rearrangement of priorities in light of this health scare. There was no easy fit into the narrative discourses described by Frank (1995) and I often felt these patients were left and marginalised within the cancer journey.

I had the opportunity to work on a project examining the experiences of people with vulnerabilities who underwent cancer care, so within this project vulnerabilities were defined as people with learning difficulties and people with severe mental illness and dementia with a co-morbidity of cancer. We examined perspectives of health professionals using focus groups (Witham et al 2014) but met with challenges in recruiting patients, particularly through gatekeeping (Witham et al 2015). For me these focus groups highlighted the challenges for people receiving cancer care and living with dementia. It was of particular note that the health professionals thought that the carers were excluded from their relative’s/friend’s treatment journey and this caused problems in both compliance and consent to treatment. This exclusion was often framed in terms of patient confidentiality without any clear assessment or disclosure of cognitive impairment. This reaffirmed my experience of nursing within oncology in which the wider social network of family and friends seemed to be minimised with an emphasis on the individual in an a-contextual way.

This becomes particularly challenging when dealing with people with fluctuating capacity and often complex social networks of support in which wider involvement of these key people by health professionals is vital for patient well-being. This has led me to explore carers' perspectives in supporting someone living with both cancer and dementia.

1.3 Study context

People living with dementia may present with a number of co-morbidities, cancer being one. Cancer is a common disease of older age with 36% of all cancers affecting people over 75 (Office of National Statistics 2010). There are over 815,000 people living with dementia in the United Kingdom (UK), affecting 1 in 14 of the population over 65 years of age (Prince et al 2014). The worldwide prevalence of people with dementia in 2010 was 35.6 million (ADI 2010) and for cancer in 2012 it was 14.1 million (Cancer Research UK 2012). Within the UK, 6.5 million people are caring, unpaid, for an ill, older or disabled family member or friend (Census 2011). Carers UK (2016) have conducted the annual state of caring survey and from 6149 responses 3 out of 4 carers did not feel their caring role is understood and valued by their community. In terms of General Practitioner (GP) support, 55% did not feel there was any practical support for them as a carer and only 31% received help in an emergency. About a quarter (21%) said that hospitals do not recognise their caring role and a similar number reported that they have physically injured themselves through caring. The UK government initiated the National Carers strategy (2008) and updated this in 2010. The 2008 strategy stated that carers were to be recognised and supported as an expert care partner, they were to be supported to have a social life outside of caring and not to be financially disadvantaged. Carers were also to be supported both mentally and physically, treated with dignity and, in particular, children were to thrive, protected from inappropriate

caring roles. The update in 2010 retained these aims but inserted priority areas including supporting early self-identification and involvement in local and individual care planning, enabling carers to fulfil their educational and employment potential, personalised carer support and the need to support carers to remain healthy.

Within the specific context of cancer, one million people in the UK are caring for a friend or family member with cancer, half of whom do not receive any support (Ipos Mori/MacMillan Cancer Support 2012). The same report identified that almost half of cancer carers (49%) support someone who is currently having treatment. The long treatment cycles often necessitate significant travelling time to and from hospital.

Within the UK, family carers are integral to supporting someone with dementia, with two-thirds of people with dementia living at home (Knapp et al 2007). Diagnosing dementia itself can be challenging and for carers this can be a convoluted task with the difficulty exacerbated by GP reluctance to diagnose due to a fear of stigma, time limitations to formally assess people, diagnostic uncertainty and therapeutic nihilism (Bradford et al 2009, Koch et al 2010). There has been associated research examining cancer experience of people with enduring and long-term mental health problems with similar issues related to dementia of late presentation and difficulties complying and maintaining often complex treatment regimes (Howard et al 2010, Sinding et al 2013, Irwin et al 2014). Stigma is also a common theme and there is evidence of diagnostic overshadowing leading to limited access to diagnostic and treatment services for physical complaints (Shipman et al 2008).

Carer burden can be significant within the context of a cancer diagnosis and there is a general acknowledgement within the cancer literature of the invisibility of carer identity (Smith 2009, Seal et al 2015), both of which impact upon carers. There are also high levels of

unmet needs including emotional and psychological issues such as anxiety and depression, fatigue, financial difficulties, issues with work, role strain and social isolation (Hubbard et al 2010, Heckel et al 2015). Care can be a time-consuming activity with repeated outpatient appointments, transport needs and the performing of extra household tasks (Stenberg, Rowland and Miaskowski 2010). Within the context of dementia care, these time-consuming extra activities involving cancer treatment can add to the burden associated with changing role patterns, the continuous nature of caregiving required and the lack of control and uncertainty of the situation (Schoenmakers et al 2010).

Within the United Kingdom, the National Dementia Strategy (2009) was introduced (DH 2009) to improve awareness of dementia (including stigma) and support earlier diagnosis and treatment and higher quality of care. Within the 17 objectives there are specific mention of carers' needs and in particular the need for good-quality information and enabling easy access to care, support and advice, carers' involvement in housing options and assistive technologies, improved community personal support services and the implementation of a carers' strategy. This has been followed by the Prime Minister's Challenge 2012, which was focused on delivery change in three key areas: creating dementia-friendly communities (in collaboration with the Alzheimer's Society), driving improvements in relation to better diagnosis, improving care in hospitals, care homes and support for carers and more information for patients and their families, and finally better research. The successor to the 2012 challenge was published in February 2015 and the Prime Minister's Challenge on Dementia 2020 set out two key broad objectives related to worldleading dementia care for people with dementia and support for people with dementia, their carers and families. The second objective related to world-leading dementia

research. In March 2016, the Department of Health published an implementation plan setting out priority actions across the 4 themes of risk reduction, health and care, awareness and social action, and research.

Achieving world-class cancer outcomes: a strategy for England 2015-2020 was published in 2015, with a subsequent implementation document in 2016 and it is an important policy driver in relation to cancer. The main tenets focus on cancer prevention, early diagnosis, patient experience, living with cancer and beyond, high-quality modern services and commissioning, provision and accountability. There is limited reference to carer involvement in outcomes related to patient experience and living with cancer and beyond and within the context of people with dementia and cancer these outcomes would seem particularly challenging to meet without close collaboration with the patient's social networks. *Improving outcomes: a strategy for cancer* (2011) again highlights similar priorities including the establishment of a National Cancer Survivorship Initiative (NCSI) specifically to support recovery, health and well-being after cancer, to support self-management and individual, personalised care planning and to support management of long-term side effects. If these types of initiatives are to be meaningful to people living with cognitive impairment then carer involvement would seem vital in promoting health and well-being and supporting effective decision-making. Within this strategy section 5.22 generally mentions other chronic conditions but does not specify carer involvement as an important element of this. Although the Carers' Strategy (2008) is referenced, the issues related to caring may be different within a cancer context and in that of supporting someone with both cancer and dementia, and the nuanced and subtle differences may not to be reflected in managing complex co-morbidities.

Reducing health inequalities is a key Government driver included in *Equity and Excellence: Liberating the NHS*, particularly those who are older and those with disabilities requiring support. The National Cancer Equality Initiative (NCEI) was established in 2008 and has attempted to promote better cancer services to disadvantaged groups supporting a human rights approach to personalised care planning. This approach is inclusive of patients' wider network of friends and family, and improving support for carers is also a priority for the Department of Health and NHS England. In February 2014 the Department of Health committed to providing people with dementia and their carers with high-quality treatment and support: this included carers' access to support services (DH 2014). This support, for carers of people living with cancer or dementia, is enshrined in the Care Act 2014 that tasks local authorities with responsibilities to support carers by undertaking carer assessments, based on the carers' perceived need for support. This assessment must establish the impact of caring and the outcomes that the carer wishes to focus on, including work, education and training or recreation. Local authorities are also required to provide information and advice and universal preventative services for carers. In May 2014 NHS England published an action plan, *NHS England's Commitment to Carers*: this articulated commitments surrounding 8 priorities in order to raise the profile of carers. In particular, it attempts to address carer concerns related to recognition by health professionals of their caring role, the need to share information and signpost carers to relevant bodies for further information and support. In practical terms, that formalised care delivery remains flexible with carer health and well-being a priority. There is also an expectation that carers will be respected as experts in care and treated with dignity and compassion. The Department of Health also made additional funding available to enable carers to take a break and has established the Carers Direct service including web-based information and advice via NHS Choices. This is

particularly important because of both hidden carers (Carduff et al 2014) and an increasingly ageing population that are becoming primary carers. Carers take on this role gradually and often do not self-identify as a carer but view themselves in relational terms as a daughter or son, husband and wife. This role ambiguity is highlighted further in the thesis.

1.4 Carer identity

The term 'carer' is usually associated with a family member who delivers unpaid care to a relative with dependency needs. The definitions of carers within the literature, however, remain ill-defined and a contested term (O'Connor 2007, Molyneaux et al 2011). O'Connor (2007) characterised this term to be defined in the literature from ranging to those who self-defined as a carer, to those who actively sought and accessed support services. I share O'Connor's assertion that carers maintain a position rather than a role and this is a socially constructed process. This position is articulated and developed through interaction rather than a pre-existing functional role that someone fits into. A new language is developed through interaction and casts an interpretative light on the person's actions generating a self-identity as a caregiver. This is produced by the socially and culturally available discourses. This position can also be perceived as facilitating benefits, particularly when engaging with formalised services. It can increase the ease of navigating formalised services and creates a sense of connection with others, thereby combating isolation. There are also tensions and as O'Connor (2007) suggests "for many, the delayed awareness of themselves as a caregiver was related to the gradual deterioration of their family member" (p168). How a person negotiates this position is complex, with Egde (2013) suggesting relationships, geography and employment play a key role in taking up carer positions and that was not

often a dynamic that was sought, embraced or even consciously taken on. Many people who undertake caregiving would not recognise the label 'carer' (Lloyd 2006), with Molyneaux et al (2011) arguing it is a bureaucratic notion deriving from a normal human experience. The heterogeneous nature of the carer population further blurs discrete categories of carer and cared for, with older carers often being simultaneously service users (Rapaport & Manthorpe 2008). Many older spousal carers see caring as a normal part of a long-term marriage whilst many black and ethnic minority people also see the label of carer as inappropriate since familial ties normalise any increased dependency of older relatives (Lloyd 2006, Arksey and Glendinning 2007). As Milne and Larkin (2015) comment, "care and caring are viewed as embedded in ordinary relationships rather than exclusively being 'an activity' that one person does to another in circumstances characterised by ill-health" (p9). It is also important to acknowledge the experience of care inside a relationship rather than positioning it as a product or activity, or superficially linking it to notions of dependency. Carers' experiences are also shaped by other factors such as the number of hours spent caring and type of care as well as age, race and gender (Milne and Larkin 2015). In light of these competing definitions and issues, for this study I would wish to interpret carer in broad terms encompassing anyone who self-identifies as a carer (this may be within a familial relationship or not) or who implicitly positions themselves through their interactions as someone who takes responsibility for the care recipient.

1.5 Research question

The research question is:

What are carer experiences of supporting someone living with cancer and dementia?

Research aims

The purpose of this study is:

1. To explore the experience of carers who have supported a relative who is living with dementia and who has also received cancer treatment.
2. To use a performative narrative approach to examine the positioning of both teller and listener and the implications this suggests for carers.
3. To examine what this positioning means in terms of healthcare professional response and the implications this may have in clinical practice.

1.6 Key issue

The key issue for this thesis is surrounding the cancer journey and how carers are (un)able to navigate this process to support their relative living with cancer and dementia. This thesis will explore how carers navigate this process. This may be through, for example decision-making and quality of life and how carers position themselves in attempting to support and maintain carer identity. This positioning will be highlighted and narratively explored.

1.7 Structure of thesis

This thesis reports on a qualitative narrative approach in exploring carer experience. In terms of structure, I have introduced the rationale for conducting the research (Chapter 1) and then the literature review (Chapter 2) has examined a broad range of literature in order

to capture the context and experience of undergoing cancer treatment with a recognised co-morbidity. I will examine the literature of those people with learning difficulties or severe mental illness or dementia who are undergoing cancer treatment and the literature related to their carers/supporters. I will examine any common themes that may resonate and apply this to the experience of carers supporting someone with dementia and cancer. I will also examine the literature related to carer experience of someone living with dementia. This will give a context to the challenges faced by carers in supporting their care recipient living with dementia and provide a frame of reference for the extra difficulties that cancer treatment can have in supporting their care recipient. Chapter 3 presents my methodology and identifies my epistemological and ontological framework. I further identify and justify my performative narrative approach based on Reissman's (2003, 2008) work and present an account of narrative approaches to data collection and analysis. I also describe positioning theory since this underpins part of my analytical approach. I further describe my methods, including the recruitment site, data collection method and issues with sampling. I also examine some of the ethical challenges present throughout the research process and present my transcription approach. Chapter 4 presents the findings section and is structured in the form of individual case studies. This is in keeping with a narrative approach, and common narrative genres and discourses are developed through these case studies and further explored in the discussion section (chapter 5). The discussion chapter examines some of the biomedical genres that shape stories and how these data develop stories within this cultural background. I examine some of the participant counter-narratives to these cultural master narratives (Nelson 2001) and how health professionals could more effectively respond to carer concerns and needs. I examine narrative approaches to health care and how this can create a more realistic and person-centred approach. The conclusion

and implications for practice forms chapter 6 and I examine decision-making, anticipatory grief and aspects of training required by health professionals to engage fully with carers of people living with cancer and dementia.

1.8 Summary of chapter

This chapter has provided my narrative for choice of topic and a context for my own positioning in both developing my research interest and justifying it. This chapter has also examined the policy drivers that provide the political context for this study, including drivers that impact on informal carers from both dementia and cancer perspectives. It has also explored the contested nature of carer identity and situated my rationale for how I have interpreted carers within this study. The following chapter provides a literature review and characterises the literature in terms of people living with cancer and dementia and further examines the context of dementia care and people's experience of living with co-morbidities and cancer.

Chapter 2

Literature review

2.1 Introduction

This literature review has a number of elements to it since there are potentially a number of subject areas to explore. Rather than covering the literature examining carers and cancer and carers and dementia, I wished to capture experiences related to having a co-morbidity and therefore this review has examined patients with cancer who have a coexisting diagnosis of dementia, severe mental illness or learning difficulties (Table 2). These co-morbidities were identified because of the associated stigma, memory or cognitive challenges that can characterise these populations (Webber et al 2014, Karnieli-Miller et al 2013, Krahn et al 2006, Clissett et al 2013, Behuniak 2011). It will also examine the experience of carers and supporters of these patients. I have then undertaken a separate search examining the context of dementia care for carers since this frames their narrative engagement and has a profound influence on navigating formalised cancer services (Table 1). No formal quality appraisal was undertaken for the papers as the aim was to scope the extant literature and summarise it; the aim was not meta- analysis or synthesis. In keeping with other authors (Rawlings and Reuber 2016) I recognise that there is no clear consensus on how to quality rate qualitative research in particular. Thus any paper that met my inclusion and exclusion criteria and which had been published in a peer-reviewed journal was included.

2.2 Search strategy

Table 2.1: Search strategy and databases (Dementia)

<p>Inclusion criteria:</p> <p>1 January 2008 – 16 November 2016</p> <p>Written in English</p> <p>Western-based papers</p> <p>Exclusion criteria:</p> <p>Intervention or evaluation studies</p> <p>Carers needs of early onset dementia</p> <p>End-of-life care</p> <p>Dementia and carers</p> <p>Science Direct 08/11/16</p> <p>English 2008-2016: dementia AND carer* (in abstract/title/key word) 186 (8 relevant)</p> <p>English 2008-2016: Alzheimer's AND carer* (in abstract/title/key word) 52 (2 relevant)</p> <p>Wiley 08/11/16</p> <p>English 2008-2016: dementia AND carer* (in abstract) 257 (12 relevant)</p> <p>English 2008-2016: Alzheimer's AND carer* (in abstract) 59 (6 relevant)</p> <p>ASSIA (Proquest) 08/11/16</p> <p>English 2008-2016: dementia AND carer* (in abstract, peer reviewed) 293 (20 relevant)</p> <p>English 2008-2016: Alzheimer's AND carer* (in abstract, peer reviewed) 33 (0 relevant)</p> <p>CINAHL 09/11/16</p> <p>English 2008-2016: dementia AND carer* (in abstract) 439 (13 relevant)</p> <p>English 2008-2016: Alzheimer's AND carer* (in abstract) 82 (3 relevant)</p> <p>Medline (Web of Knowledge) 11/11/16</p> <p>English 2008-2016: dementia AND carer* (in topic) 1151 (65 relevant)</p> <p>English 2008-2016: Alzheimer's AND carer* (in topic) 296 (18 relevant)</p>
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2848 articles were identified on initial search and, after applying the inclusion/exclusion criteria, 69 were included as relevant.

One of the objectives of this literature review is to compare the literature related to people with cancer and a co-existing condition of either dementia, severe mental illness or learning difficulties. I undertook a separate search from the one described in table 2.1 (with broader date ranges) for articles in English from CINAHL, Medline, ASSIA, Wiley and Science Direct (search 2). I searched from (Jan) 2000 to (Nov) 2016 to capture the limited range of papers within this subject area. Inclusion criteria were that papers focused on aspects of the cancer journey for patients or carers, exclusion criteria related to papers predominately reporting on cancer prevention or detection, risk/prevalence studies, palliative-care-focused or review papers. Since there is a dearth of evidence available, papers that related to patient experience were also included to contextualise the wider environment in which carers have to cope and respond. I used a narrative approach producing an interpretative review, involving “the selection, chronicling and ordering of evidence to produce an account of the evidence” (Dixon-Woods et al 2005: 47).

Table 2.2: Search strategy and databases (Learning Difficulties)

Databases searched: MEDLINE (Web of Knowledge), CINAHL, SCIENCE DIRECT, ASSIA (ProQuest), WILEY

Search terms:

Cancer AND dementia

Cancer AND Alzheimer's

Cancer AND "learning disabilit*"

Cancer AND "intellectual disabilit*"

Cancer AND "intellectual disabilit*" AND carer*

Cancer AND "learning disabilit*" AND carer*

Cancer AND "learning disabilit*" AND famil*

Cancer AND "intellectual disabilit*" AND famil*

"Learning disabilit*" AND carer*

"intellectual disabilit*" AND carer*

Schizophrenia AND cancer

"severe mental illness" AND cancer

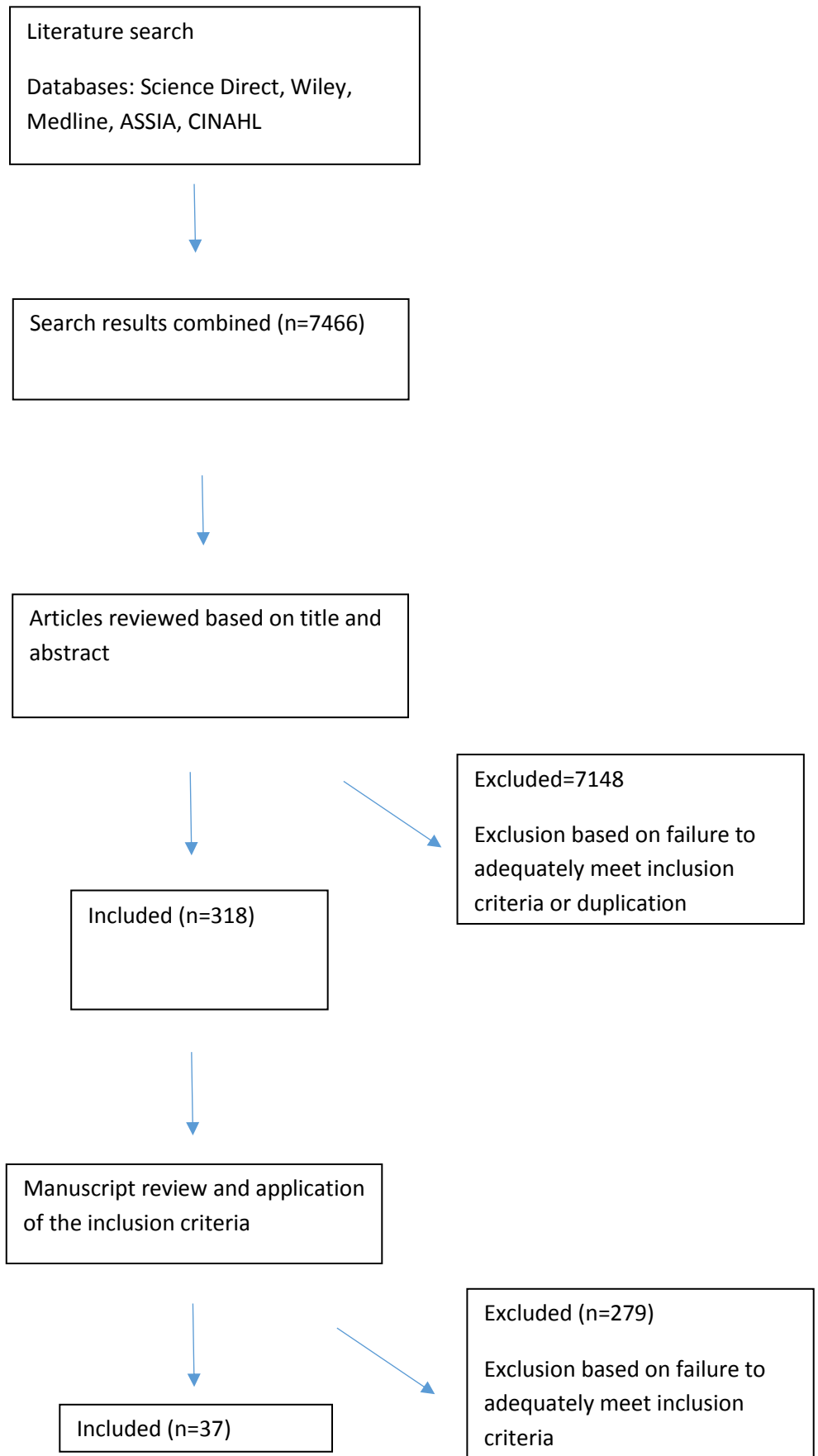


Figure 2.1: Flow diagram of the literature review process

2.3 Included papers

Table 2.3: Cancer and learning difficulties

Authors	Title	Methodology/method	Participants	Country
Jones et al (2006)	Meeting the cancer information needs of people with learning disabilities: experiences of paid carers	Participant observation of using a booklet “getting on with cancer” and then separate interview with supporter and person with learning difficulties	5 participants with learning difficulties and their supporters	United Kingdom
Tuffrey-Wijne I and Davies J (2007)	This is my story: I’ve got cancer ‘The Veronica Project’: an ethnographic study of the experiences of people with learning disabilities who have cancer	Single case study using Thematic field analysis	1 participant with learning difficulties	United Kingdom
Tuffrey-Wijne I, Bernal J, Hubert J, Butler G, Hollins S (2009)	People with learning disabilities who have cancer: an ethnographic study	Ethnographic study using participant observation (over 250 hours in 7 months) following grounded theory principles	13 participants with mild to moderate learning difficulties	United Kingdom
Tuffrey-Wijne I, Bernal J, Hollins S (2010)	Disclosure and understanding of cancer diagnosis and prognosis for people with intellectual disabilities: Findings from an ethnographic study	Ethnographic study using participant observation	13 participants with mild to moderate learning difficulties	United Kingdom
Cresswell A and Tuffrey-Wijne I (2008)	The come back kid; I had cancer but I got through it	Single descriptive case study	1 participant with learning difficulties	United Kingdom

Sullivan SG and Hussain R (2008)	Hospitalisation for cancer and co-morbidities among people with learning disability in Australia	Case review (n=9409) from a cancer registry	173 had learning difficulties	Australia
Martean et al (2013)	Jo's Story: the journey of one woman's experience of having cancer and a 'learning disability'	Single case study using thematic field analysis	1 participant with learning difficulties	United Kingdom
Witham et al (2014)	The challenges of health professionals in meeting the needs of vulnerable patients undergoing chemotherapy: a focus group study	2 focus groups with health professionals using a narrative approach	18 health professionals (9 in each focus group)	United Kingdom
Flynn et al (2015)	Caring for cancer patients with an intellectual disability: Attitudes and care perceptions of UK oncology nurses	Used a questionnaire with vignettes (to explore stigma)	83 oncology nurses	United Kingdom
Flynn et al (2016)	"You don't know what's wrong with you": an exploration of cancer-related experiences in people with an intellectual disability	Qualitative Interviews	6 people with learning disabilities and 12 participants within their supportive network	United Kingdom

Table 2.4: Severe Mental Illness and cancer

Authors	Title	Methodology/methods	Participants	Country
Kisely et al (2008)	Excess cancer mortality in psychiatric patients	Population based record linkage study with primary care and specialist mental health services from 1995-2001.	4690	Canada
Mateen et al (2008)	Do patients with schizophrenia receive state-of-the-art lung cancer therapy? A brief report	Retrospective study of patients in one centre	29 patients with pre-existing schizophrenia and a lung cancer diagnosis between 1980 and 2004	USA
Tran et al (2009)	Cancer mortality in patients with schizophrenia: an 11-year prospective cohort study	Prospective study initiated in 1993-2004 recruited from 122 (14.7%) adult psychiatry departments in France	3470 patients with schizophrenia	France
Sharma et al (2010)	Schizophrenia does not adversely affect the treatment of women with breast cancer: a cohort study	Retrospective study of patients in one centre	37 women with schizophrenia and breast cancer diagnosed between 1993 and 2009	United Kingdom
Baillargeon et al (2011)	Effects of mental disorders on diagnosis, treatment and survival of older adults with colon cancer	Retrospective cohort study using the Medicare database 1993-2005	20,699 patients who had a diagnosis of any mental disorder 2 years preceding this colon cancer diagnosis	USA
Batty et al (2012)	Impact of mental health problems on case mortality in male cancer patients	Cohort study based on non-adopted men born in Sweden from 1950 to 1976 identified through 2 national registers	16,498 men with cancer registrations	Sweden
Kisely et al (2013)	Cancer-related mortality in	Population based record linkage design, mental health records were	6586 new cancers in psychiatric patients	Western Australia

	people with mental illness	linked with cancer registrations and death from 1988 to 2007		
Farasatpour et al (2013)	Breast cancer in patients with schizophrenia	Cohort study based on a register (Patient Treatment File) of the Department of Veteran Affairs and chart-based review	56 patients, 37 (66%) were female	USA
Chang et al (2014)	A cohort study on mental disorders, stage of cancer at diagnosis and subsequent survival	Longitudinal study with a data linkage between two case register systems (2001-2007)	2206 participants who previously been assessed or treated by secondary mental health services prior to cancer diagnosis and 125 had severe mental illness	United Kingdom
Bergamo et al (2014)	Inequalities in lung cancer care of elderly patients with schizophrenia: an observational cohort study	Observational cohort study using the Surveillance, Epidemiology, and End Results (SEER) database linked to Medicare records	1303 (1.3%) had non-small cell lung cancer and schizophrenia	USA
Abdullah et al (2015)	Adjuvant radiation therapy for breast cancer in patients with schizophrenia	Cohort study based on patient treatment file, the national inpatient computer database of the Department of Veterans Affairs	40 patients with schizophrenia who later developed breast cancer and were candidates for adjuvant radiation therapy according to international guidelines	USA
Cunningham et al (2015)	Cancer survival in the context of mental illness: a national cohort study	Breast and colorectal cancer registrations (2006–2010) were linked to psychiatric hospitalization records for adults (18–64 years)	440 participants (breast cancer), 190 (colorectal cancer) had recent contact with psychiatric services	New Zealand

Iskikawa et al (2016)	Differences in cancer stage, treatment and in-hospital mortality between patients with and without schizophrenia: retrospective matched-pair cohort study	A retrospective matched-pair cohort of gastrointestinal cancer patients was identified using a national in-patient database	Multivariable ordinal/binary logistic regressions was modelled to compare cancer stage at admission, invasive treatments and 30-day in-hospital mortality between patients with schizophrenia ($n=2495$) and those without psychiatric disorders ($n=9980$)	Japan
Ribe et al (2016)	Ten-year mortality after a breast cancer diagnosis in women with severe mental illness: a Danish population-based cohort study	Estimated all-cause mortality rate ratios (MRRs) of women with SMI, women with breast cancer and women with both disorders compared to women with neither disorder using data from nationwide registers in Denmark for 1980–2012	2.7 million women, 31,421 women with severe mental illness (12,852 deaths), 104,342 with breast cancer (52,732 deaths), and 1106 with Severe mental illness and breast cancer (656 deaths)	Denmark

Table 2.5: Cancer and people with dementia

Author	Title	Methodology/method	participants	Country
Gilles and Johnson (2004)	Identity loss and maintenance: commonality of experience in cancer and dementia	Parallel thematic findings from two qualitative studies exploring the experience of disease as it relates to cancer and dementia	16 individuals with cancer and 20 with dementia and the impact on family carers	United Kingdom
Gupta and Lamont (2004)	Patterns of presentation, diagnosis and treatment in older patients with colon cancer and comorbid dementia	Cohort study using National Cancer Institute (NCI) Surveillance, Epidemiology, and End-Result (SEER) Medicare data from 1993 to 1996. Medicare files were evaluated to determine which patients had an antecedent diagnosis of dementia	A total of 17,507 individuals aged 67 and older with invasive colon cancer (Stage I-IV)	USA
Gorin et al (2005)	Treatment for breast cancer in patients with Alzheimer's disease	Retrospective cohort study using the Surveillance, Epidemiology, and End Results (SEER), a population-based cancer registry covering 14% of the US population	50,460 breast cancer patients aged 65 and older, of whom 1935 (3.8%) had a diagnosis of AD before or up to 6 months after cancer diagnosis	USA
Louwman et al (2005)	Less extensive treatment and inferior prognosis for breast cancer patients with co-morbidity: a population-based study	Population-based study examining the age-specific prevalence of serious co-morbidity using the National Programme of Cancer Registry	New breast cancer patients diagnosed from 1995 to 2001 (n=8966)	Netherlands
Raji et al (2008)	Effect of a Dementia Diagnosis on Survival of older patients after a	Retrospective cohort study using data from the linked Surveillance, Epidemiology and End	106,061 patients aged 68 years or older diagnosed as having breast, colon or prostate cancer	USA

Smyth (2009)	diagnosis of breast, colon or prostate cancer Current practices and perspectives on breast cancer screening and treatment in older women with dementia	Results– Medicare database Thematic analysis of semi structured telephone interviews.	23 family caregivers of women with dementia	USA
Robb et al (2010)	Patterns of care and survival in cancer patients with cognitive impairment	Retrospective case-control study comparing a sample of older cancer patients with cognitive impairment to a non-cognitively impaired control group as to patterns of care and survival by age, site and stage.	258 geriatric oncology patients aged 70 and older whom an established geriatric oncology programme at an NCI-designated Comprehensive Cancer Centre has seen.	USA
Baillargeon et al (2011)	Effects of mental disorders on diagnosis, treatment and survival of older adults with colon cancer	Retrospective cohort study using the Medicare database 1993-2005	20,699 patients who had a diagnosis of any mental disorder 2 years preceding this colon cancer diagnosis	USA
Iritani et al (2011)	Impact of dementia on cancer discovery and pain	Case notes review of the records of cancer patients with and without dementia treated at the surgical ward of Matsuzawa Hospital from 1993 to 2004	134 cancer patients with and without dementia (50 demented and 84 non-demented) were included	Japan
Patnaik et al (2011)	The influence of co-morbidities on overall survival among older women diagnosed with breast cancer	The Surveillance, Epidemiology, and End Results-Medicare database was used to identify primary breast cancers diagnosed from 1992 to 2000 among	The study population included 64,034 patients with breast cancer diagnosed	USA

Torke et al (2013)	Caregiver perspectives on cancer screening for persons with dementia: "Why put them Through it?"	women aged 66 years or older Focus group study (4 focus groups)	32 caregivers with mean age 65.5 years (range 49–85 years)	USA
Chang et al (2014)	A cohort study on mental disorders, stage of cancer at diagnosis and subsequent survival	Using the anonymised linkage between a regional monopoly secondary mental health service provider and a population-based cancer register, a historical cohort study was constructed	2206 participants had been previously assessed or treated in secondary mental healthcare before their cancer diagnosis and 125 for severe mental illness	United Kingdom
Kimmick et al (2014)	Co-morbidity burden and guideline-concordant care for breast cancer	Cross-sectional design using the National Program of Cancer Registry (NPCR) Breast and Prostate Cancer Patterns of Care study, which re-abstracted medical records from 2004 in seven cancer registries	The study sample included 6439 women with stage 0-III breast cancer	USA
Witham et al (2014)	The challenges of health professionals in meeting the needs of vulnerable patients undergoing chemotherapy: a focus group study	2 focus groups with health professionals using a narrative approach	18 participants (9 in each focus group)	United Kingdom

Courtier et al (2016)	Cancer and dementia: an exploratory study of the experience of cancer treatment in people with dementia	A single-site case study design to examine practices in four clinics using multi-methods of data collection: retrospective note review, observation, interviews and recorded consultations. A framework analytic approach identifies themes within and across cases	33 clinical encounters with patients with memory loss were observed. Ten consultations were audio-recorded and 16 individuals interviewed (n = 6 patients-carer dyads, n = 1 lone patient, and n = 5 staff). Medical records were reviewed for 338 cases	United Kingdom
Hopkinson et al (2016)	People with dementia: what is known about their experience of cancer treatment and cancer treatment outcomes? A systematic review	Systematic review. The analytic plan and inclusion/exclusion criteria were specified in advance of the search process in a protocol.	Nine studies conducted in four resource rich countries were included in the review. Data was extracted independently then conducted a content analysis and narrative synthesis.	United Kingdom

2.4 Learning disabilities and cancer

The detailed search strategy including exclusion/inclusion criteria, databases and number of relevant papers identified are outlined below.

Inclusion:

2000-2016

English language

Focus on experiences of cancer journey

Exclusion

Cancer prevention/detection

Palliative-care-focused

Review papers

Medline (Web of Science)

26/08/16: English 2000-2016: "Learning disabili*" AND carer* 26 (3 relevant)

English 2000-2016: "intellectual disabili*" AND carer* 1 (0 relevant)

English 2000-2016: "learning disabili*" AND famil* 184 (1 relevant)

English 2000-2016: Cancer AND "learning disabili*" 41 (8 relevant)

English 2000-2016: Cancer AND "intellectual disabilit*" 226 (29 relevant)

English 2000-2016: Cancer AND "intellectual disabilit*" AND carer* 12 (4 relevant)

English 2000-2016: Cancer AND "learning disabilit*" AND carer* 12 (8 relevant)

English 2000-2016: Cancer AND "learning disabilit*" AND famil* 25 (4 relevant)

English 2000-2016: Cancer AND "intellectual disabilit*" AND famil* 26 (3 relevant)

Science Direct

26/08/16: English 2000-2016: "learning disabilit*" AND carer* (in title/abstract/keywords)
33 (4 relevant)

English 2000-2016: "intellectual disabilit*" AND carer* (in title/abstract/keywords) 55 (4 relevant)

English 2000-2016: "intellectual disabilit*" AND famil* (in title/abstract/keywords) 279 (2 relevant)

English 2000-2016: "learning disabilit*" AND famil* (in title/abstract/keywords) 85 (1 relevant)

English 2000-2016: cancer AND "learning disabilit*" (in title/abstract/keywords) 9 (5 relevant)

English 2000-2016: Cancer AND intellectual disabilit* (in title/abstract/keywords) 37 (7 relevant)

English 2000-2016: Cancer AND "learning disabilit*" Carer* (in title/abstract/keywords) 3 (3 relevant)

English 2000-2016: Cancer AND "learning disabilit* famil* (in title/abstract/keywords) 2 (1 relevant) 4 (1 relevant)

English 2000-2016: Cancer AND "intellectual disabilit*" famil* (in title/abstract/keywords) 2 (1 relevant)

ASSIA (ProQuest)

01/09/16 English 2000-2016: Cancer AND "learning disabilit*" 23 (7 relevant)

English 2000-2016: Cancer AND "intellectual disabilit*" 30 (4 relevant)

English 2000-2016: Cancer AND "learning disabilit*" AND carer* (in scholarly journals) 24 (7 relevant)

English 2000-2016: Cancer AND "intellectual disabilit*" AND carer* (in scholarly journals) 17 (6 relevant)

English 2000-2016: Cancer AND "learning disabilit* AND famil* (in scholarly journals) 145 (3 relevant)

English 2000-2016: Cancer AND "intellectual disabilit*" AND famil* (in scholarly journals) 105 (4 relevant)

CINAHL (13/09/16)

English 2000-2016: Cancer AND "learning disabilit*" 55 (13 relevant)

English 2000-2016: Cancer AND "intellectual disabilit*" 95 (27 relevant)

English 2000-2016: Cancer AND "learning disabilit*" AND carer* 9 (7 relevant)

English 2000-2016: Cancer AND "intellectual disabilit*" AND carer* 10 (9 relevant)

English 2000-2016: Cancer AND "intellectual disabilit*" AND famil* 14 (9 relevant)

English 2000-2016: Cancer AND "learning disabilit*" AND famil* 7 (3 relevant)

Wiley (13/09/16)

English 2000-2016: Cancer (in abstract) AND "learning disabilit*" (in abstract) 36 (11 relevant)

English 2000-2016: Cancer (in abstract) AND "intellectual disabilit*" (in abstract) 53 (16 relevant)

English 2000-2016: Cancer AND "learning disabilit*" AND carer* (in abstract) 7 (6 relevant)

English 2000-2016: Cancer AND "intellectual disabilit*" AND carer* (in abstract) 7 (7 relevant)

English 2000-2016: Cancer AND "intellectual disabilit*" AND famil* (in abstract) 11 (6 relevant)

English 2000-2016: Cancer AND "learning disabilit*" AND famil* (in abstract) 5 (no relevant)

This search, after removal of duplication, yielded 49 papers. After application of the inclusion/exclusion criteria 10 papers were included in this review. All the papers (except for Flynn et al 2015 and Sullivan & Hussain 2008) were qualitative in design, from focus groups (Witham et al 2014) to participant observation (Jones et al 2006, Tuffrey-Wijne et al 2009, Tuffrey-Wijne et al 2010), case study, narrative life story approaches (Martean et al 2013, Tuffrey-Wijne & Davies 2007, Cresswell & Tuffrey-Wijne 2008) and interviews (Flynn et al 2016). Flynn et al (2015) used questionnaires based on vignettes to explore stigma and to assess attitudes and care perceptions of UK oncology nurses, whilst Sullivan & Hussain (2008) analysed hospital data sets to establish hospital admission for cancer and co-morbidity for people with learning difficulties. In terms of qualitative findings Tuffrey-Wijne et al (2009) presents an ethnographic approach using grounded theory with 13 people with learning disabilities from mild to severe who had a cancer diagnosis. Through participant observation the findings suggest that the lives of these participants were mediated by the

care support staff who enabled social engagement and relationship building (particularly with moderate to profound learning difficulties). The discovery of cancer within this context relied on others to observe and act on signs and symptoms, and typically within this sample 10 participants presented late with a cancer diagnosis. Medical staff appeared to rely on carers in making decisions with minimal engagement with participant wishes. Five participants did not have treatment on either the insistence of carers or an assumption by doctors that they would not cope. A lack of effective communication skills in breaking bad news was also implicated in the communication challenges for people with learning difficulties and cancer. Tuffrey-Wijne (2010), using a grounded theory approach, examines disclosure and understanding of cancer and prognosis for people with intellectual disabilities. This appears to be from the same data set of her previous paper (Tuffrey-Wijne et al 2009) but examining a more specific issue in depth. Truth telling was arbitrary and often dependent on the paid social care workers' personal preferences rather than an assessment of the person's wishes. For people with mild to moderate intellectual disabilities the implications of cancer were difficult to assimilate, with often conflicting or minimal information provided by health professionals. For those people with more severe intellectual disabilities, gauging understanding remained challenging with carers not feeling it appropriate for them to know. There were apparent issues of paternalism by both relatives and support staff, with treatment and care decisions controlled by families and paid social care staff unless taken by medical staff. There was also limited opportunities for participants to make decisions about treatment. Martean et al (2013) explore a case study using a narrative approach examining a case study of one woman's lived experience of cancer. They suggest open, honest communication by health professionals would open up choice and aid decision-making.

Witham et al (2014) explore health professionals experience of vulnerable groups undergoing chemotherapy within a tertiary oncology centre, and one group identified was people with learning difficulties. A narrative approach to the focus groups was taken and participants indicated that trying to assess understanding in relation to informed consent for treatment decision-making was difficult and exacerbated by the perception of an increased patient volume. Creating the time and the environment to assess whether the information had been retained and understood was challenging and adapting treatment pathways to meet the social and psychological needs of people with learning difficulties was time-consuming, requiring complex interdepartmental and interprofessional co-ordination. Flynn et al (2015) further examines the attitudes and care perceptions of UK oncology nurses using a questionnaire with vignettes (to explore stigma). They had a sample size of 83 and the results indicated that, in terms of care perceptions, participants felt more confident in their knowledge, training and experience and better able to identify and meet the needs and communicate with patients without an intellectual disability. It was further suggested that a patient with an intellectual disability would be more stressful and challenging to support and care for. The interactional effects suggested that previous experience by participants with people with intellectual disabilities generated more confidence when providing care and they felt more positively about providing care. This experience further suggested less stress and the ability to provide appropriate support in comparison to those participants with no previous experience. Interestingly, this sample felt less comfortable communicating directly with patients with intellectual disability, with greater reliance on communicating with the patient's caregiver. None of the participants reported that they would consult the patient themselves about how best to support them.

Jones et al (2006) examined the experiences of paid carers in meeting the cancer information needs of people with learning disabilities. Five people with learning disabilities and cancer participated together with their supporters (mainly paid staff). Data collection included non-participant observation of a person with learning disabilities and a supporter using the book (*Getting on with Cancer*) as an information tool. At the end of the session the researcher conducted tape-recorded semi-structured interviews with both the person with learning disabilities and their supporter. Using thematic analysis the findings suggest the high burden and challenge of often young support workers in confronting issues of bereavement and loss. Expectations of supporters were high but understanding cancer information (and its impact) and effectively translating that to the person with learning difficulties was something many felt ill equipped to do.

Sullivan & Hussain (2008) examined the records of 9409 people in Australia linked with the Hospital Morbidity Data System after previously identifying people with learning disability linked with the Western Australian Cancer Registry. There were 173 cancer (excluding 25 leukaemia patients whose hospital admissions were very frequent) and 9198 non-cancer patients. The data tentatively suggest that co-morbidities remain high within this group with incomplete data sets suggesting this to be an underestimation of the scale and extent. People with learning difficulties were no less likely to be diagnosed with cancer than the general population but significant morbidity may be a feature and experience of cancer treatment and indeed could influence whether treatment was initiated in the first place. This has implications for support for both the person with intellectual difficulties and carers/supporters and highlights some of the complexity in managing cancer treatment within this patient group.

Tuffrey-Wijne & Davies (2006) present preliminary findings of an ethnographic study (subsequently published; Tuffrey-Wijne et al 2009) with a single case study. It recalls the diagnoses and treatment journey of John (the co-author), who had penile cancer. His narrative is recalled in his own words and describes the late diagnosis, the shock of cancer and challenges of communication with his family. Martean et al (2013) also used a narrative approach, examining a case study of one woman's lived experience of cancer. They suggest open, honest communication by health professionals would open up choice and aid decision-making. Cresswell and Tuffrey-Wijne (2008) also use a single case study approach with Cresswell describing her experience and the need for health professionals to be open and proactive in their information giving, be honest and actively listen to the concerns of people with learning disabilities and cancer. Flynn et al (2016) interviewed 6 participants with mild learning difficulties living with cancer and their nominated caregivers and health professionals. From the health professional perspective poor training and prior experience of supporting people with learning difficulties made the support process challenging. This was exacerbated by limited patient involvement in treatment decision-making. More person-centred, inclusive interactions were appreciated by both patients and carers although there was a tendency towards paternalistic approaches to care decision-making based on the perceived psychological stress of the person with learning difficulties.

Within the limited literature base there are issues identified related to poor communication and particularly with the person with learning difficulties and health professionals but also in conveying sensitive and complex information to professional carers. Although the data do not appear to specially identify informal carers, there may be application to this group with negotiating information needs, accessing comprehension and accurate treatment information, challenging for carers of people with learning difficulties.

2.5 Severe mental illness and cancer

In terms of informal carers, the burden in supporting someone with severe mental illness is significant (Gupta et al 2015). In particular, with a condition like schizophrenia, prominent positive or negative symptoms have been associated with lower quality of life in carers, and more lost work days, with the greatest carer burden associated with the highest symptomatology (Rabinowitz et al 2013). Positive symptoms can be characterised as prominent delusions, hallucinations and positive formal thought disorder whilst negative symptoms can be characterised with symptoms such as affective flattening and attention and linguistic impairment. There are, however, more positive associations with caregiving, including becoming more sensitive to persons with mental illness, clarity of purpose and relationship building between carer and recipient. This is associated with higher quality of life among caregivers (Kate et al 2013). Gupta et al (2015) examined health status of caregivers of people with schizophrenia compared with non-carers and caregivers of adults with other conditions (Alzheimer's disease, cancer and stroke). When compared to non-carers and carers of other conditions schizophrenia caregivers reported more sleep difficulties, insomnia, anxiety and depression. These findings are representative of other published work on schizophrenia caregiver burden (Caqueo-Urizar et al 2009). One of the main findings was the positive experience of caring but a substantial proportion of caregivers indicated that they lacked social and financial support, leading to isolation from family and friends. Overall the caregivers of people living with schizophrenia reported worse health-related quality of life than non-caregivers and caregivers of other conditions. Papastavrou (2012), however, compared schizophrenia, Alzheimer's and cancer caregivers and found that caregivers of cancer patients experienced the highest levels of depression,

while Alzheimer's caregivers experienced the highest levels of overall burden ($p < 0.001$).

Supporting someone with schizophrenia and severe mental illness can be a challenging and time-consuming task equating to an average of 6-9 hours a day and up to 43% caring over 32 hours per week (Magliano et al 1998, Roick et al 2007). This has obvious impact in maintaining a working life and the subsequent job opportunities available. Previous qualitative research findings demonstrated that tiredness, sadness, persistent stress, uncertainty and frustration are the common feelings of burden expressed by caregivers (Johansson et al 2010). In a similar cultural frame to dementia the stigma associated with perceptions of mental illness is another predisposing factor associated with caregiver burden (Yesufu-Udechuku et al 2015).

Further work suggests similarities with carers of people with dementia in that older and female caregivers, caregivers with depressive symptoms and caregivers with a higher self-perceived stigma are more likely to experience a higher level of caregiver burden (Hasson-Ohayon et al 2011, Magana et al 2007).

The detailed search strategy including exclusion/inclusion criteria, databases and number of relevant papers identified is outlined below.

Wiley (12/09/16)

English 2000-2016 schizophrenia AND cancer (in abstract): 103 (12 relevant)

English 2000-2016 "severe mental illness" AND cancer (in abstract): 24 (1 relevant)

English 2000-2016 cancer AND "bipolar disorder" (in abstract): 50 (1 relevant)

Science Direct (26/09/16)

English 2000-2016 schizophrenia AND cancer (in abstract): 165 (14 relevant)

English 2000-2016 "severe mental illness" AND cancer (in abstract): 7 (3 relevant)

English 2000-2016 cancer AND “bipolar disorder” (in abstract): 60 (4 relevant)

ASSIA (28/09/16)

English 2000-2016 schizophrenia AND cancer (in abstract): 27 (7 relevant)

English 2000-2016 “severe mental illness” AND cancer (in abstract): 5 (0 relevant)

English 2000-2016 cancer AND bipolar (in abstract): 14 (2 relevant)

CINAHL (13/09/16)

English 2000-2016 schizophrenia AND cancer (in abstract): 55 (3 relevant)

English 2000-2016 “severe mental illness” AND cancer (in abstract): 9 (2 relevant)

English 2000-2016 cancer AND bipolar (in abstract): 19 (1 relevant)

Medline (EBSCO host) (13/09/16)

English 2000-2016 schizophrenia AND cancer (in abstract): 530

(15 relevant)

English 2000-2016 cancer AND “severe mental illness” (in abstract): 25 (5 relevant)

English 2000-2016 cancer AND bipolar (in abstract): 149 (5 relevant)

Inclusion criteria

English

2000-2016

Exclusion criteria:

Risk/prevalence studies

Reviews

Cancer screening

After applying the inclusion/exclusion criteria 14 papers were included.

After an initial scoping exercise no papers were identified that included carers of people with severe mental illness who had cancer. Most studies presented data sets examining treatment outcomes. The data present a mixed picture in terms of stage of diagnosis of people with cancer and severe mental illness. Chang et al (2014) assessed stage at cancer

diagnosis and survival after cancer diagnosis among people accessing secondary mental health services. It was a longitudinal study with a data linkage between two care register systems in the United Kingdom. The primary outcome measure was stage when the cancer was diagnosed. There were no associations found between specific mental disorders and metastatic spread of cancer at presentation. People with severe mental disorders, depression, dementia and substance use disorders had significantly worse survival after cancer diagnosis, independent of stage at diagnosis. Therefore, associations between mental disorders and cancer mortality are more likely to be accounted for by differences in survival after cancer diagnosis rather than by delayed diagnosis. Causes for this might include reduced access to medical treatment and care, differing decisions about suitable treatment pathways and the effect of other co-morbidities. There may also be differences between cancers on the impact to survival for early diagnosis but there were insufficient data to analyse such differences among types of cancer. Sharma et al (2010) have suggested that schizophrenia does not adversely affect the treatment of women with breast cancer but their sample size was small (n=37) and ascertainment bias, a feature of cohort studies, may limit the interpretation. The results suggest women with schizophrenia and breast cancer do not often present too late for standard adjuvant treatment. Whilst this may be so (although Irwin et al 2014 and Farasatpour et al 2013 suggest women with severe mental health issues do present with more advanced disease at time of diagnosis), cancer survival remains poorer for these than for those without mental illness (Baillargeon et al 2011; Batty et al 2012; Chang et al 2014, Ribe et al 2016). Abdullah et al (2015) examined patients with schizophrenia who are candidates for adjuvant radiotherapy therapy (ART) following a breast cancer diagnosis in the USA. They searched patient treatment files and the national inpatient computer database of the Department of Veterans (DVA) and identified 40

patients with schizophrenia who later developed breast cancer and were candidates for ART. Of the 40 patients, 35 had data about the decision to offer ART, with only 22 (63%) offered ART and 5 of those 22 (23%) refused it. This retrospective review had limitations: in particular, 11 (27%) of the sample were men, which is unrepresentative of the breast cancer population (about 2% male) and highlights the predominately male population of the DVA. Nevertheless the results highlight the non-compliance with treatment that make cancer treatment challenging within this population and they suggest that involvement of family may be of benefit.

Ribe et al (2016) conducted a population-based cohort study using information on Danish women from nationwide registers. They were examining the ten-year mortality after a breast cancer diagnosis in women with severe mental illness (SMI). The cohort included 2.7 million women and, compared to women with neither disorder (cancer or SMI), the mortality was 118% higher for women with SMI, 144% higher for women with breast cancer and 327% higher for women with SMI and breast cancer. Among women with both conditions, 15% of deaths could be attributed to interaction. In contrast to Chang et al (2014) and Sharma et al (2010), Ribe et al (2016) indicate that an increase in mortality for women with SMI and breast cancer is suggestive of late presentation precipitated upon suboptimal health-seeking behaviours and health utilization. They speculate that this may be also attributed to poor health information, for example not understanding signs and symptoms of breast cancer and not performing breast self-examination. Their results, however, did not suggest that adjusting for tumour stage played a major role for the association between SMI and mortality after breast cancer diagnosis. This point is further suggested by Ishikawa et al (2016) in their examination of the differences in cancer stage, treatment and in-hospital mortality between patients with and without schizophrenia within

Japan. They used a retrospective matched-paired cohort of gastrointestinal cancer patients identified using a national inpatient database. Higher mortality was observed both in those individuals with schizophrenia whose cancer was at an early and at an advanced age. The authors suggest that patients with early stage cancer would not only have died because of their cancer prognosis (within 30 days after admission) but also that their deaths would probably be related to adverse treatment outcomes.

Batty et al (2012) examined the impact of mental health problems on case fatality in male cancer patients and in their large Swedish sample. They examined psychiatric admissions before cancer diagnosis by registration and found significantly worse survival, especially for those who had previous depressive disorders, neurotic and adjustment disorders and in the presence of substance misuse. Kisely et al (2008) conducted a Canadian-population based record linkage study with primary care and specialist mental health services from 1995 to-2001. Cancer mortality was 72% higher in males and 59% higher in females among patients with contact with mental health services.

Kisely et al (2013) undertook a population-based record linkage analysis from Western Australia (from 1988 to 2007) to address the question of why psychiatric patients are no more likely than the general population to develop cancer but more likely to die from it. These data indicated a lower cancer diagnosis in those with mental health issues but a higher mortality and late diagnosis (7.1% v. 6.1% with metastases on diagnosis) especially for breast and lung cancer. There was also a reduced likelihood of surgery, especially of colorectal, breast and cervical cancers. They also received less radiotherapy and chemotherapy than the general cancer population. Baillargeon et al (2011) undertook a retrospective cohort study examining the effects of mental disorders on diagnosis, treatment and survival of older adults with colon cancer. They used the Surveillance,

Epidemiology and End Results (SEER)—Medicare-linked database and established that people with mental disorders were more likely to have been diagnosed with colon cancer at autopsy and at an unknown stage of cancer; to have received no surgery, chemotherapy, or radiation therapy and to have received no chemotherapy for Stage 3 cancer. The rate of overall mortality and colon-cancer-specific mortality was substantially higher in participants with a pre-existing mental disorder than in their counterparts. All of these associations were particularly pronounced in participants with psychotic disorders and those with dementia. Farasatpour et al (2013) used an American database to select patients with schizophrenia who later develop breast cancer. These data were augmented with chart-based clinical data. Delay in diagnosis was common, with distant metastases present in 21% (N=56). Treatment compliance was challenging, with 12 patients initially refusing all treatment. Tran et al (2009) present a large French prospective study commenced in 1993 with an initial cohort of 3470 participants with schizophrenia to examine cancer-related mortality and predictors. During the 11-year follow-up 476 (14%) patients died (this included all causes of death including accidental and suicide); the mortality rate was nearly four times higher than in the general population. Cancer was the second most frequent cause of mortality (n=74) and the risk was 1.5 times higher than in the general population. The increased risk of mortality was particularly related to women with breast cancer and men with lung cancer. Mateen et al (2008) refer specifically to lung cancer treatment and schizophrenia suggesting that within their single-centre, small-sample population treatment options were never solely based on the pre-existing schizophrenia but based on a series of contextual clinical decision-making processes (for example, infection or a change of treatment from chemotherapy to radiotherapy due to the patient's schizophrenic symptoms). Bergamo et al (2014) undertook an observational cohort study to examine inequalities in lung cancer care of elderly patients

with schizophrenia. They used the SEER database linked to Medicare (USA) and whilst this population appeared to be diagnosed at an early stage they were less likely to receive stage-appropriate diagnostic evaluation and treatment. The early stage of diagnoses may be related to continuing medical management and the awareness of increased smoking and associated lung cancer. The predominance of squamous cell carcinoma that is centrally located and causes early symptoms may also be a factor within this sample. The researchers suggest that navigating the complex cancer pathways and treatment regimens may be challenging for people with severe mental health issues. They also suggested that other barriers were related to gaining informed consent, that treatment adherence may account for poorer access and subsequent outcomes of people with schizophrenia.

Cunningham et al (2015) present a national cohort study, examining New Zealand breast and colorectal cancer registrations (2006-2010) and linked this to psychiatric hospitalization records for adults (18-64 years). Cancer-specific survival was compared for recent psychiatric service users and non-users using cox regression. The contributions of deprivation, co-morbidity and stage at diagnosis were assessed for those with schizophrenia or bipolar affective disorder and others using mental health services. Those people with a recent history of psychiatric service use had poorer survival after diagnosis with breast or colorectal cancer than those who did not have such a history. Those who had been diagnosed with schizophrenia or bipolar disorder prior to cancer diagnosis had two and half times (breast) cancer to three times (colorectal cancer) the risk of dying from their cancer within 5 years. Late stage at diagnosis explained more than a third of the survival difference for this group but was not a factor for service users with other diagnoses. Markiewicz and Hintze (2016) examined stigma and social support in both schizophrenia and women with breast cancer and found schizophrenia led to significantly more stigma than breast cancer

treatment. Women after breast cancer treatment who experienced stigma felt less supported and often protected friends and family from difficult psychological or social aspects of their lives post treatment.

This review highlights the poor survival rates post cancer diagnosis of people with severe mental illness. This appears a consistent feature and replicated internationally in Japan (Ishikawa et al 2016), New Zealand (Cunningham et al 2015), Europe (Chang et al 2013, Ribe et al 2016, Tran et al 2009, Batty et al 2012), USA (Baillargeon et al 2015, Abdullah et al 2015, Bergamo et al 2014, Farasatpour et al 2013), Canada (Kisely et al 2008) and Australia (Kisely et al 2013). The literature remains more circumspect in relation to the factors that contribute to poor survival with late diagnosis reported (Baillargeon et al 2011, Farasatpour et al 2013, Tran et al 2009, Ribe et al 2016, Ishikawa et al 2016, Kisely et al 2008 & 2012). Cunningham et al (2015), however, report that late diagnosis was seen in those with schizophrenia or bipolar disorder rather than other mental health conditions. Chang et al (2013) further suggest from their data that associations between mental disorders and cancer mortality are more likely to be accounted for by differences in survival after cancer diagnosis rather than by delayed diagnosis. They suggest that studies like Baillargeon et al (2011) did not adjust for potential confounders in their analyses, especially for type of cancer. Interestingly Ishikawa et al (2016) found inpatient mortality rates were higher even for those with early stage disease: that would suggest other factors may be affecting outcome rather than late diagnosis. Any pre-existing illness can impact on cancer stage at diagnosis, with diagnostic overshadowing (when general physicians might minimise the clinical significance of physical complaints when assessing and treating patients with psychiatric conditions) a possible cause (Howard et al 2010, Irwin et al 2014). Alternatively,

there can be increased medical surveillance leading to early diagnosis, for example, the medical monitoring of symptoms of lung cancer in a population that often smokes heavily (Bergamo et al 2014). The mental state of people with severe mental illness can again be a variable to either late or early cancer diagnosis (Cunningham et al 2015).

The literature also suggests that non-compliance can be an issue as well as dealing with negative symptoms of, for example, schizophrenia, including social withdrawal and decreased expression of emotion, making informed consent challenging (Farasatpour et al 2013, Abdullah et al 2015). Sharma et al (2010) however, have suggested that, within their cohort of patients with breast cancer, schizophrenia did not pose a significant treatment risk, with few participants declining treatment and effective support and communication being facilitative of this process. Issues related to cancer treatment have been raised by Howard et al (2010) who comment that standard procedure for radiotherapy is to lie still on a couch for consecutive days lasting potentially for weeks, and these daily treatments can be stressful for people with severe mental health problems. The necessity to remain alone in a room during the procedure with automated instructions can generate anxiety for patients with a tendency for paranoia and auditory hallucinations. Other treatment issues like face masks to keep the head in position for head and neck radiotherapy and the claustrophobic nature of CT or MR scans can also be challenging. Stigma may be a factor within cancer care for people with severe mental health issues (Irwin et al 2014, Ellison et al 2013), with people living with schizophrenia reporting high rates of healthcare discrimination (Thornicroft et al 2009, Thornicroft 2011). The limited treatment options offered to people with severe mental illness highlighted by Bergamo (2014), Mateen et al (2008) and Kisely et al (2013) could highlight the disparities in care exacerbated by patients

with bizarre affect or poor hygiene or when there is clinical uncertainty related to the best treatment (Jones et al 2008). If oncologists believe that people with, for example, schizophrenia would become too agitated, aggressive or non-compliant they may refer a patient to a more conservative suboptimal treatment option. The conclusion of Abdullah et al (2015) highlights this issue: rather than examining supportive and communication strategies for people with severe mental illness they focus on non-compliance with complex treatment regimens and suggest “breast-preserving treatment plans may be impractical” (p378). There are little available data about the patient experience of cancer treatment for someone with severe mental health illness, and no data on how this experience impacts upon caregivers. From the population-based studies and the speculative discussion generated there may be a number of issues which make the treatment journey challenging, and how caregivers are included within this process could have a significant impact.

2.6 Cancer and people with dementia and cognitive impairment

People living with dementia may present with a number of co-morbidities, and cancer is a common disease of older age with 36% of all cancers affecting people over 75 (Office of National Statistics 2010). The probability of co-occurrence of both dementia and cancer in the same patient therefore increases with age. With reference to the type of dementia there is, however, a growing body of research demonstrating an inverse association between cancer and Alzheimer’s disease (Roe et al 2010, Driver et al 2012, Musicco et al 2013, Shi et al 2015). Roe et al (2010) found in a population-based cohort study that people with cancer had a 43% lower risk of ever developing Alzheimer’s disease and that people with Alzheimer’s disease had a lower risk of incident cancer. The risk of Alzheimer’s disease was lowest in survivors of smoking-related cancers, and was not primarily explained by

survival bias. Driver et al (2012) identified a 33% decreased risk of developing probable Alzheimer's disease compared with people without cancer. Similar findings were identified by Shi et al (2014) who undertook a systematic review with meta-analysis finding that patients with Alzheimer's disease exhibit an overall 45% decreased risk of cancer compared with general population or individuals without Alzheimer's disease. There are issues as to whether this is a true association since severe cognitive impairment could lead to a decrease in cancer screening and reported cancer symptoms (Driver et al 2012). Are lower cancer rates in people with Alzheimer's disease caused by decreased incidence or under-diagnosis? Within the study by Driver et al (2012) patients with dementia were less likely to develop screening-related cancers than those without dementia, suggesting that at least some of the perceived decreased risk is because of under-diagnosis.

The detailed search strategy including exclusion/inclusion criteria, databases and number of relevant papers identified are outlined below.

Dementia and cancer

Wiley 13/10/2016

English 2000-2016: Cancer AND dementia (in abstract) 117 (5 relevant)

English 2000-2016: Cancer AND Alzheimer's (in abstract) 279 (3 relevant)

Science direct 13/10/16

English 2000-2016: Cancer AND dementia (in abstract) 297 (3 relevant)

English 2000-2016: Cancer AND Alzheimer's (in abstract) 504 (0 relevant)

ASSIA (ProQuest) 16/10/16

English 2000-2016: Cancer AND dementia (in abstract) 92 (6 relevant)

English 2000-2016: Cancer AND Alzheimer's (in abstract) 28 (0 relevant)

CINAHL (16/10/16)

English 2000-2016: Cancer AND dementia (in abstract) 314 (8 relevant)

English 2000-2016: Cancer AND Alzheimer's (in abstract) 130 (5 relevant)

Medline (Web of Knowledge) (16/10/16)

English 2000-2016: Cancer AND dementia (in title) 43 (12 relevant)

English 2000-2016: Cancer AND Alzheimer's (in title) 96 (4 relevant)

Torke et al (2013) examined issues related to cancer screening in dementia from a caregiver perspective through using focus groups. They identified that caregivers made decisions about cancer screening based on quality of life and that many had experiences of stopping or wishing to stop cancer screening in the setting of dementia. This was often focused on the burden of screening in the presence of cognitive impairment without mental capacity. Caregivers were also cautious of health professionals who pursued diagnostic tests without accounting for the overview of the goals of treatment. Their decision-making was based on the benefits and burdens for the patient. Witham et al (2014) examined health professionals' experience of patient vulnerability within cancer care, and there was a perception that the needs of caregivers were often secondary to the procedural aspects of cancer management, with caregivers often excluded from the decision-making process.

In terms of people living with dementia, cognitive impairment may interfere with the diagnosis and treatment of older patients with cancer. Raji et al (2008) conducted a retrospective cohort study of 106,061 patients using data from linked surveillance and identified a much poorer survival rate after a cancer diagnosis for patients living with a pre-existing diagnosis of dementia. There was also an associated increased mortality from

cancer and from non-cancer causes but the absolute increase in deaths associated with a dementia diagnosis was considerably larger from non-cancer causes of death than from deaths from cancer. Importantly a dementia diagnosis was associated with increased odds of being diagnosed at an unknown stage of cancer and highlights the often late diagnosis of cancer within this group. Baillargeon et al (2011) examined data related to patients with mental disorders and colon cancer, finding this group were more likely to have been diagnosed with colon cancer at autopsy and at an unknown stage of cancer. The data also suggested they were more likely not to have received any cancer treatment: these associations were particularly pronounced in participants with dementia. The interpretation of these results requires some caution since the study did not adjust for potential confounders in their analysis, especially for type of cancer. Gupta and Lamont (2004) used a large database analysing individuals aged 67 and over listed in the SEER-MEDICARE database and diagnosed with colon cancer, and found dementia patients to be twice as likely to have colon cancer reported only after death. They were twice as likely to have cancer diagnosed using non-invasive methods and twice as likely to have their cancer reported as unstaged. People living with stages 1-3 disease and with a dementia diagnosis were also 43% as likely to receive surgical resection as non-impaired patients and those dementia patients with resected stage 3 colon cancer were only 20% as likely to receive adjuvant 5FU-based chemotherapy. Gorin et al (2005) examined older women with breast cancer (65+) also using the SEER-MEDICARE database and found that, after controlling for age, race and cancer stage, patients with dementia were 52% less likely to have surgical resection, 41% less likely to have radiation, 39% less likely to have chemotherapy and 2.7 times more likely to receive no treatment. Smyth (2009) explored the nature of breast cancer screening and treatment decisions in older women with dementia through a thematic analysis of semi-

structured telephone interviews. Carers' views on cancer treatment varied according to their perception of the severity of the care recipient's dementia. For mild to moderate dementia, some carers would opt for aggressive treatment but others only if the side effects were minimal. For carers of women with advanced dementia only comfort care was mentioned as a viable option should breast cancer be diagnosed. The sample was 23 family caregivers of women with dementia. Robb et al (2010) examined a more targeted population than the SEER-MEDICARE registries with data on both functional status and co-morbidity. They identified a much narrower difference in patterns of treatment compared to the control group, and assert the importance of mortality within this patient group. Their results showed an increased mortality risk in patients with cognitive impairment versus those not cognitively impaired across age groups, tumour stage and site. Chang et al (2014) conducted a historical cohort study on mental disorders, stage of cancer at diagnosis and subsequent survival using an English population-based cancer register. Dementia was examined as a subgroup within data analysis and was associated with worse survival after cancer diagnosis with relatively little attenuation following adjustment for stage at cancer diagnosis. One of the issues with this subgroup may have been the availability of stage information and more generally, in common with the other subgroups, the lack of available lifestyle factors, which were an unaccounted variable. There was, however, clear indications, similar to Robb et al (2010), that, although the stage of diagnosis for cancer of people with mental illness was not more advanced, these people were still at higher risk of death compared with their counterparts without mental illness. It may be, as Robb et al (2010) suggest, an indication of co-morbidity and advancing dementia but it is also unclear whether other factors suggested by Chang et al (2014) are significant, such as reduced access to medical treatment, differing decisions about or tolerance of intensive regimes and

the influence of other health problems or drug effects on survival. Iritani et al (2011) compared behaviours of cancer patients with and without dementia in relation to the process of diagnosis, the recorded pain complaints (excluding those clearly unrelated to cancer) and the documented use of analgesia and opioid use. They reviewed nursing and medical records of all patients admitted to oncological surgical unit and compared cancer patients without and with dementia. The sample consisted of 134 patients with cancer admitted to a public psychiatric hospital with a facility to treat physical conditions in Japan from 1993 to -2004. Only 8% of patients with dementia and cancer sought a medical opinion pre-diagnosis compared with 63% cancer patients without dementia. Pain was recorded in 76% of patients without cognitive impairment compared with 22% of patients with dementia. Analgesic use increased with stage progression in cancer patients without dementia, with 64% receiving analgesia for early stage disease and 84% for late stage disease. Forty-one per cent used strong opioids for advanced disease. For patients with dementia only 11% received analgesia for early stage disease and 13% for advanced disease, with only one receiving strong opioids. Louwman et al (2005) present an observational cohort study describing the prevalence of serious co-mortality in patients with breast cancer and its impact on treatment and effect on prognosis, independent of the patient's age and stage of disease. The data were generated from the National Programme of Cancer Registry and the outcomes related to prevalence of co-morbidity analysed by age group, difference in treatment in those with and without co-morbidity analysed by age group and crude survival stratified by age at diagnosis. Survival of the sub-population of 70 patients with dementia was shorter compared with those without co-morbidity (HR 2.34, 95% confidence interval 1.6 to 3.5, $p=0.0001$ adjusted for age, disease stage and treatment). The presence of co-morbid conditions alters the treatment pathway independently of the patient's age and

disease stage and this may or may not be good clinical practice. The risk of death from breast cancer is higher for someone with a dementia diagnosis independent of age or disease stage and treatment.

Kimmick et al (2014) conducted a cross-sectional retrospective record review of randomly selected cases and examined the relationship between co-morbidity and guideline-concordant care for early stage breast cancer. The sample included 6439 women with stage 1-3 breast cancer diagnosed in 2004. Guideline concordant treatment (based on international guidelines) included surgery, adjuvant radiotherapy, lymph node clearance, chemotherapy and hormone treatment. They included treatment concordance in 26 co-morbid conditions including dementia. Treatment remained guideline-concordant for 69.5% without co-morbidity, with less concordance associated with dementia. This can be for a number of reasons including quality of life and treatment compliance issues. Patnaik et al (2011) presented a retrospective cohort study based on the US SEER registers (based on Medicare claims databases) to measure associations between specific co-morbidities and overall survival and all-cause mortality for older women diagnosed with breast cancer. The sample size was 64,034 women with breast cancer diagnosed between 1992 and 2000 aged 66 and older. In terms of findings, women with breast cancer and dementia were at higher risk of all-cause mortality compared with those without dementia, adjusting for age, race and ethnicity, tumour stage and grade and treatment.

Gilles and Johnston (2004) examined parallel thematic findings from two qualitative studies exploring the experience of disease as it relates to cancer and dementia. The original studies examined the experiences of 16 individuals with cancer and 20 with dementia and this paper examines common or shared concepts of identity loss and maintenance. Both

populations experienced a sense of role erosion and both expressed an awareness that their status within the family was changing as their integral role diminished and they were perceived by other family members as being increasingly dependent. Maintaining or preserving identity was also an issue, with both cancer and dementia respondents appearing to reclaim their identity through references to an earlier life. Carers asserted a change in identity within both groups, with an increased sense of emotional isolation: with dementia it was more related to communication challenges and for cancer the fear of causing added distress by raising the topic of illness. The physical changes and frailty associated with both conditions challenged personhood and led to 'social death' (Sweeting and Gilhooly 1997) and further isolation and identity changes. Carers attempted to compensate for these changes, so carers of someone with dementia described how they "filled the gaps" in order to maintain and keep up appearances, or, as Orona (1990) describes it, "working both sides of the relationship" (p1255) once reciprocity is lost. For carers of someone with cancer this may present as a pretence of long-term goals within the context of advancing disease.

Courtier et al (2016) undertook a single-site case study design to explore the experiences of cancer treatment in people with dementia. They retrospectively reviewed all available electronic and paper-based medical records to estimate the prevalence of dementia during a 4-month period. They all used non-participant observation of patient consultations over a 4-month period, capturing data with field notes. They also followed this up with immediate post-observation interviews after the consultations with staff members to understand management decisions and social actions. They then proceeded with after-observation interviews with patients and their carers to explore what is experienced as facilitative of

cancer treatment, care compliance and self-care. In total there were 33 clinical encounters between staff and patients with memory loss. Ten consultations were audio-recorded and 16 individuals interviewed. Medical records were reviewed for 338 cases. The findings suggest that the exploration of memory loss was superficial, based upon patient or carer disclosure. Patients were found to underplay the importance and extent of memory problems in cancer consultations. Staff associated memory loss with older age and found assessment challenging. There appeared an avoidance to explore memory without an obvious benefit in doing so. There is a lack of communication of a dementia diagnosis in referrals to cancer centres and a worry that patient disclosure would adversely affect treatment decisions. There were also issues related to monitoring side effects and carer communication, with subtle negotiations between staff and the person with dementia particularly surrounding decision-making. There was a clear lack of proactive communication and support from staff to carers, and carers appeared not to seek support themselves.

The findings of a systematic review (Hopkinson et al 2016) indicate that, compared to cancer patients who do not have dementia, people treated for cancer with pre-existing dementia are diagnosed at a later or unknown stage and receive less treatment, with more treatment complications and poorer survival. The role of family carers has not been explored within the literature. Poor survival may be related to under-treatment but there are no studies focusing on amended treatment pathways, and survival could also be indicative of dementia progression. There are practical issues related to quality of life, treatment tolerance and behavioural or psychological issues that may compromise optimal treatment compliance. Late diagnosis may also be connected to an inability to articulate

health concerns in the presence of cognitive impairment (Iritani et al 2011) and the subsequent delay in seeking help. The current literature characterises and suggests that the less likelihood of cancer treatment for people living with pre-existing dementia are related to issues of quality of life and the additional staff time to support this population (Baillargeon et al 2011). This is compounded by a more complex consent process with the need for a wider network of people involved and compliance with legal frameworks such as the Mental Capacity Act (2005). Issues of risk management are also invoked with cognitive impairment, suggestive of compromised abilities to self-care related to side effects, complications of treatment and follow-up (Ballargeon et al 2011, Iritani et al 2011).

2.7 The context of informal care

2.7.1 Diagnosing dementia

Diagnosing dementia is important for a number of reasons identified in the literature including the right to know, confirming suspicions and allowing better future planning. It can allow for positive adaptations within family and spouse relationships and access to early treatments with the added benefit of managing the disease when the patient has moderate symptoms. It can also lead to large savings for health providers, with similar findings from multiple countries (from the UK: Pinner & Bouman 2003 and Elson 2006; from USA and Canada: Connell et al 2004 and Byszewski et al 2007; from France: Rapp et al 2012; from Taiwan: Lin et al 2005; and from the Netherlands: Derksen et al 2006). Diagnosing dementia, however, can be challenging and it is often slow to diagnose (Wilkinson et al 2004). A systematic review by Dungen et al (2012) aimed to estimate family physicians' diagnostic accuracy at the different stages of dementia. A dementia diagnosis was documented in only up to one-third of mild dementia patients and in less than two-thirds of

moderate to severe dementia patients. Bradford et al (2009) identify four levels at which barriers to dementia diagnosis can occur (from an American perspective): the patient level, the caregiver level, the level of the healthcare system and the physician level. Important barriers at the patient and caregiver levels included misinterpretation or denial of symptoms, fear of stigma, therapeutic nihilism and fear of institutionalisation. Important barriers at the level of healthcare system are the limited reimbursement and time available per patient, with older patients often presenting with co-morbidities limiting the time to establish a clear diagnosis. At the physician level, failure to recognise symptoms, diagnostic uncertainty, fear of stigmatising or harming the patient and therapeutic nihilism were all a feature.

A systematic review examining the barriers in primary care (Koch et al 2010) reinforced these previous findings, identifying a number of issues including a lack of support, time and financial constraints, stigma, diagnostic uncertainty and disclosure of the diagnosis. The lack of support related to areas such as inadequate information and access about community services and resources (Hinton et al 2007, van Hout et al 2000) to the absence of interdisciplinary teams to enhance management (Allen et al 2005). Time management was an issue with GPs inadequately prepared to undertake procedures, tests and reviews within their normal schedule in order to diagnose dementia (Allen et al 2005, Hinton 2007, van Hout 2000, Turner 2004). Stigma was attributed by the patient or caregiver on receiving a diagnosis of dementia (Teel 2004) and may be a reaction to fear of labelling or entering a nursing home (Iliffe et al 2005). The uncertainty of diagnosis focused on inadequate post-graduate training (Cahill et al 2008, Iliffe et al 2005, Kaduszkiewicz et al 2008) and a difficulty in distinguishing the slowly progressive, fluctuating nature of dementia from

'normal' ageing (Allen et al 2005, Iliffe et al 2005, Chrisp et al 2012). The disclosing of the diagnosis was challenging in terms of the appropriate time and place (Iliffe et al 2005) to give the diagnosis, the reaction of patients and family in denial or wanting a cure. Another issue was diagnosis disclosure to family members but not patients, with Allen et al (2005) finding 72% of Primary Care Physicians (PCPs) routinely informed family members of the diagnosis with fewer (31%) informing the patient. Delays in presentation can be attributed to family denial, to family immersion in compensating for the loss of function of the patient, so they do not notice that there is anything wrong and believing the symptoms are part of normal ageing (van Hout 2007, Teel, 2004). Rapp et al (2014) also found that where there was a family history of Alzheimer's disease this slowed diagnosis but informal care speeds it up. They interpreted the data as indicating that those who had already experience of a family member with dementia were aware of the issues and lack of effective therapy (particularly if it related to siblings) and therefore did not feel it would be advantageous to pursue a diagnosis. Informal carers were often aware of the cognitive changes apparent and were more encouraging to the person living with dementia to formally diagnose the condition.

Hansen et al (2008) used focus groups to explore issues of dementia diagnosis and the GPs in their study were more focused on the overall health of a patient (often presenting with co-morbidities) rather than a discrete illness or condition. If a patient's overall health was good a dementia diagnosis was of less concern even if dementia was suspected. The diagnosis could be detrimental to the patient in accessing services because of stigma and a shortage of dementia-specific services. This may account for the reluctance of GPs to refer to specialist services (Carvana-Pulpan & Scerri 2014). The nature of dementia meant that

few patients attended their doctor complaining of symptoms but rather family members informed the GP about their relatives' behaviour (Moore & Cahill 2013). There was a perception that a dementia diagnosis was difficult to hear. The discussion was therefore sometimes avoided, and especially when coupled with poor pharmacological options making little therapeutic benefit to early diagnosis. Le Couteur et al (2013) also question the benefits of early diagnosis on pharmacological grounds since medications like cholinesterase inhibitors can increase the risk of hip fractures, syncope and pacemaker insertion (Gill et al 2009). There are also risks and costs associated with investigations for dementia. There are usually three or four diagnostic tests (Wimo 2013) and the one-off cost for a dementia diagnosis is £3200 in the UK (Prince et al 2011). The diagnostic processes can be distressing, alarming and stigmatising (Manthorpe et al 2013) with the infantilisation of patients constructed even from the initial process of cognitive testing for diagnosis within memory clinics (Orr 2010). A population-based study by Pimouguet et al (2014) demonstrated that participants who consulted a specialist for their cognitive problems presented an overall poorer survival compared with those without cognitive complaints to a physician, even after adjustment on potential confounders. This clarifies some of the issue argued by Rait et al (2010) in that within this study worse survival could not be associated with late care access. Pimouguet et al (2014) hypothesise that early specialist consultation could be the consequence of a faster dementia progression than captured on assessment tools or had greater burden of other health conditions. It could also be explained by suboptimal medical follow-up and by the presence of events that both precipitate consultations and influence survival prognosis.

Werner (2013) undertook a systematic review examining the current knowledge and future directions about the disclosure of dementia and identified that those studies including physicians' preferences and practices regarding the diagnosis of dementia showed that the majority of physicians supported disclosure but did not implement it in their own practice. Communication training in breaking significant news may be of importance and certainly, within cancer care, training in breaking significant news has had a positive effect in improving confidence (Voorhees et al 2009). Ladds et al (2013) examined attitudes by UK and Danish GPs to early diagnosis, and once again diagnostic uncertainty, insufficient knowledge and experience of GPs, difficulties in disclosure post-diagnosis or the inhibiting effects of societal stigma and therapeutic nihilism all impact on diagnostic rates.

Mastwyk et al (2014) conducted semi-structured interviews with 32 memory clinic patients and their carer at two time points and noted the poor information recall relating to a dementia diagnosis in the consultation at a memory clinic. This is consistent with other studies; for example, Bradford et al (2011) found that less than half the patients and carers they interviewed could recall the patient's diagnosis. This was in spite of 84% being prescribed a memory-enhancing medication that 90% of carers and 66% of patients could recall. These data are suggestive of information overload and may also reflect the difficulties of information recall in the face of significant news. Mastwyk et al (2014) also identified that both carers and patients preferred a direct approach in information giving and this did not change at time point 2. Rosness et al (2009) measured the effects of stress that carers experience before the first visit to a memory clinic with the person with memory problems (using the Relative Stress Scale) and identified that spouses of patients referred had considerable stress independent of whether the patient met the criteria for dementia.

Carers scored high on the measures utilised within this study, and this was particularly evident when related to impaired activities of daily living for the care recipient. A finding consistent with other research was that being a woman caring for someone living with memory problems was an independent predictor of stress and particularly 'depressive stress'. Stokes et al (2014) examined the dementia diagnosis from the caregiver's experience, and using an IPA approach highlight the lack of information and support following diagnosis, the personal adjustments that diagnosis brings and the difficulties with stigma and accessing service provider provision.

Pesonen et al (2013) in a Finnish study used a grounded theory approach to explore the diagnosis of dementia and argued that dementia can be seen as a collaborative journey where spouses work together through difficulties. There was an undermining of personhood as well as, for carers, role and identity changes as well as increased responsibility and maintaining emotional balance in the family. Bunn et al (2015) tested and contextualised the findings of a systematic review of qualitative studies examining patient and carer experience of diagnosis and treatment (Bunn et al 2012). This involved focus groups and semi-structured interviews, and the findings were categorised as 'pathways through diagnosis', 'conflicts that need to be resolved to accommodate the diagnosis', and 'living with dementia'. Stigma, the normalisation of symptoms and a lack of awareness continued to be barriers to diagnosis. The sense of self was profoundly challenged for the person living with dementia, and the participants highlighted inadequate post-diagnostic support.

Dean et al (2014) examined the experiences of people with mild cognitive impairment and their caregivers. The qualitative interviews highlighted the carer difficulties in being taken seriously by GPs and in the consultation dynamic where the carer is reporting behaviour in

front of the person with cognitive impairment. In terms of the memory clinic, the actual diagnostic tests were felt to be unpleasant for them and the care recipient. Information provision was again a challenging area in terms of what these tests mean and the long-term implications, with often no follow-up appointment. Campbell et al (2016) map the transition from pre-diagnosis to a diagnosis of dementia through five people with dementia and their carers and two people living alone who presented at a memory clinic. All 12 participants were interviewed at 2 time points, at time of presentation and then shortly after diagnosis. The data were analysed using a ground theory method, and 'living with uncertainty' was a core category, with many unanswered question for both carer and person with dementia throughout this process.

2.7.2 Accessing services: dementia

Beattie et al (2005) examined professional accounts of access to services of a subset of dementia care, younger people and black and minority ethnic groups. They undertook qualitative interviews with service managers, care staff and workers in black mental health teams and elder organisations using a mixture of snowball and purposive sampling. There appeared a mismatch between service user need and service provision founded on a small number of service users and their geographical dispersal. There was a suggestion that minority groups are concentrated in urban areas and therefore outside these areas relevant services were limited. Where transport was provided to attend specific services there was a perception that this led to exclusion of local people from services. There was an absence of choice within these groups, with the emergent perception of the unsuitability of the small number of specialist dementia services that did exist. For those people living with dementia

supported by family the professional accounts characterised family carers as approaching services only at crisis point. This reinforces the idea that services are for high-‘risk’ people with advanced dementia. There was a perception that GPs deemed dementia as untreatable and therefore did not refer on.

Lloyd & Stirling (2011) explored carers’ concerns in relation to service use. They suggest ambiguous gains for carers, with formal carers entering the home and being potentially supportive but also potentially undermining of carer identity. Their private world and space becomes a site of formalised care with often multiple agencies and carers entering the home causing uncertainty. There were also perceptions from carers of a sense of failure in engaging formalised services, that this undermined their moral agency as a carer. The identity of carers as competent and committed is diminished. For carers the ‘secure self’ is also disrupted by the fluctuating capacity of the person living with dementia in maintaining identity work. This relational uncertainty and their subsequent engagement with the dementia carer role had affected their friendship networks, requiring identity work in re-establishing meaningful and affirming relationships. For service providers the criteria for service provision can be arbitrary and withdrawn as a result of a number of factors (for example, funding formula): however, the initial establishment of formalised care services requires making connections with carers and establishing relationships. Carers perceive these relationships as significant and often replacing friendships and family and therefore the removal or uncertainty in relation to continued provision is a source of great concern.

Willis et al (2009) conducted a qualitative evaluation to generate quality indicators for dementia care in relation to a memory service. This single-centre study found that group therapy and day centres created a peer support network which was important to carers and

helped normalise the experience of dementia. Information giving was also considered a key carer need at all time points from diagnosis, treatments and service provision. This research was further supported by Abley et al (2013), who examined communication and information provision within memory services and found inadequate information provision especially in the absence of a clear diagnosis or other dementias rather than Alzheimer's disease. The delay in diagnosis was often a feature of the experience, with most appreciating clear and honest communication about any diagnosis. Voluntary organisations were one of the most valued sources of information. Sami et al (2013) further explored the experiences of assessment and the diagnostic journey. They undertook qualitative interviews with 27 people with cognitive impairment and 26 carers using four memory services. Most participants approached their GPs as a gateway to accessing specialist services but the actual referral process was unclear with no participants receiving follow-up letters from their GP and the purpose and possible outcome of the referral had not been explained. Most participants experienced the assessment process as confusing and labyrinth-like with increasing anxiety approaching the point of diagnosis. Diagnostic tests were not explained nor were the implication of these tests. The waiting times from first consultation in primary care to point of diagnosis were from 3 to 9 months, with frustration focused on not knowing whom to contact to chase up results or appointments. The diagnostic disclosure was experienced both negatively and positively, with some participants shocked with feelings of loss and grief. There was a clear need to diagnose dementia and find out about its long-term consequences although the avenues for access to further questions or information were often not forthcoming. A lack of information post-diagnosis was a common experience of the participants. In terms of long-term management, remaining independent was a key priority. Carers appeared to struggle in remaining involved, motivated and proactive in

promoting their relatives' independence. Those participants who had not received practical advice reported frustration, helplessness, loss of independence and autonomy and an inability to assert control over their future. Hailey et al (2015) examined a comparison of survey data from patient and carer feedback questionnaires collected from services as part of the accreditation process of memory services in the United Kingdom. From the 583 patient and 663 carer questionnaires returned, patients and carers who attended memory services rated excellent the written information they received about a variety of topics, had been asked for feedback, found appointments easier to obtain and more likely to be offered an assessment of their needs than those attending just accredited services.

Brodaty et al (2005) undertook a literature review examining why carers do not use formalised services. The most prevalent reason for non-use of community services was perceived lack of need followed by the care recipient's reluctance to accept help from services. Other reasons included lack of knowledge or being in the process of considering and applying for services. The refusal of formalised care was in spite of low levels of satisfaction for the care-giving role and the impact on quality of life. The presence of a physical disability in the care recipient was associated with service use, as was contact with a social worker. The review suggests that the priorities for action should be raising community awareness on service availability, normalising service use, destigmatising dementia and encouraging health professionals to follow the example of social workers in making referrals. Cooper et al (2009) indicated that presentation to services for ethnic minorities was lower than in the indigenous population in the UK and other English-speaking countries. Mukadam et al (2011a) explored why ethnic elders present later to dementia services and identified that carers felt the symptoms were part of normal ageing, that denial

by the person with memory problems was an issue and carers sometimes were reluctant to seek help and risk upsetting their relatives. There were some cultural expectations that delayed diagnosis: for example, there was a cultural expectation within Asian families that the woman with dementia would cede household duties to her daughter-in-law and therefore the loss of such skills was not perceived as a problem. There was an expectation that it was a familial responsibility to look after the person with dementia and that outside help might be intrusive. The stigma of mental illness was also a feature of some carer accounts. The GP was the commonest pathway to diagnosis, with delays occurring due to the inability of health professionals to pick up cognitive impairment.

Mukadam et al (2011b) within a systematic review further characterised the belief within ethnic minority groups that dementia represented normal ageing, with one study identifying the perception that dementia was a psychological, social or spiritual issue rather than an illness requiring medical support. Language barriers and experience of racism or discrimination were also issues identified, as was uncertainty about how to access help. There was also evidence of health professionals dismissing symptoms (Cloutterbuck & Mahoney 2003) as well as participants not seeking advice since there was no effective treatment (La Fontaine et al 2007). Referrals occurred at times when carers could no longer cope rather than with the emergence of symptoms. Interestingly the themes were similar from different ethnic minority groups and from different countries. Lawrence (2008) found that carers from ethnic minorities with a more traditional 'ideology' were more likely to be satisfied with formal services and often placed limits on the level of support that they asked for and received. They felt it important to maintain greater independence and control of the caregiving situation. Some carers with non-traditional ideologies about the caregiver role

(for example, an absence of reward in the caregiving role, that their life is on 'hold') were more willing to use formal care services, were more demanding of those services and were more dissatisfied with care. There was a consensus that accessing services was a 'battle' they were constantly fighting to receive information, advice and practical assistance.

2.8 Carer experience: dementia

2.8.1 Care burden

A large part of the literature on carer experience within dementia care has predominately focused on carer burden as an affectively negative and stressful experience. There is a tendency to conceptualise carer need largely through quantitative, decontextualised measures of carer 'burden'. Lavarone et al (2014) explored caregiver burden and coping strategies in caregivers of patients with Alzheimer's disease and used a cross-sectional survey with a small sample size of 86 caregivers. The data indicated an extremely high global burden including feelings of failure with prevalence in women and older caregivers. Time dependence and physical burden are greater in older caregivers, whereas developmental and emotional burdens predominate in women caregivers. Relatives, regardless of the role they play inside the family group, heavily perceived burden. This burden was also acknowledged by people living with dementia in relation to their carers, with people with mild to moderate dementia aware of the psychological health of the family member. Care recipients' perceptions of their carer's level of anxiety and overall psychological health was consistent with the carer's own perceptions (Ablitt et al 2010). Carers who were psychologically distressed are also more likely to act abusively towards the care recipient living with dementia (Cooper et al 2010). Some of the literature focused on dementia subtypes and carer impact. For example, Lee et al (2012) examined carer stress in dementia

and, in particular, the role of diagnosis and neuropsychiatric symptoms. They found that caring for people with dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD) was associated with significantly more stress than caring for people with Alzheimer's disease (AD) and vascular dementia (VaD). Psychosis and mood fluctuations associated with DLB were significantly correlated with carer stress whilst mood was significantly correlated with carer distress in carers of people with AD and VaD. Overall carer stress was associated with higher levels of psychosis, mood disturbances, daytime sleep and cognitive fluctuations in the person with dementia. Eneida et al (2013) also established that burden particularly worsened for carers of patients with advancing fronto-temporal dementia, and this also impacted on their ability to maintain empathy (Hsieh et al 2013). Rosness et al (2008) found that carers of patients with fronto-temporal dementia were significantly less satisfied with the provision of information about the disease, counselling and follow-up compared with carers of early onset Alzheimer's disease. Svendsboe et al (2016) also found that carers for people with dementia with Lewy bodies experience a significantly greater burden compared with those caring for people with Alzheimer's disease. Other areas of cognitive and demographic variables that contribute to carer burden relate to age, memory and emotion recognition (Miller et al 2013). Overall this evidence may suggest that it is the behavioural and psychological symptoms of dementia rather than the stage in the trajectory of dementia that influences carer burden (Sutcliffe et al 2016).

Li et al (2012) conducted a systematic review examining coping strategies and psychological morbidity in family carers of people with dementia. From the 35 studies generated from their inclusion or exclusion criteria, dysfunctional coping was moderately correlated with depression and anxiety. Their meta-analysis suggests that solution-focused coping is not

cross-sectionally associated with carer mental health and therefore challenged the idea that solution-focused coping has positive implications for carer mental health. Cooper et al (2008) had explored such a relationship longitudinally and found that carers who reported using more solution-focused coping strategies, relative to other forms of coping at baseline, tended to show more symptoms of anxiety and depression at 12 months follow-up. This may reflect the progressive nature of dementia and the increased stress and difficulty of a problem-solving approach in the light of this. Madsen & Rikke (2013) highlight the experiences of grief, change and burden that affect the caregiver whatever the familial relationship to the relative, and Raggi et al (2015) found the amount of burden for caregivers is positively correlated with the severity of impairments of the patient in the cognitive, behavioural, functional, motor and medical domains. The severity of caregiver stress was also correlated with specific coping strategies, such as seeking for social support, using avoidance behaviours and focusing on problems.

Gallagher et al (2011) examined self-efficacy as a protective factor against carer burden and depression and found caregiver burden was predicted by self-efficacy for symptom management, caregiver educational level, emotion-focused coping, dysfunctional coping and patient function. McClendon & Smyth (2013) identified caregiver personality traits and coping strategies associated with better quality of care through a survey approach of 148 family caregivers. In particular, the personality traits of agreeableness, openness, conscientiousness and neuroticism were related to higher-quality care and the trait of extraversion was related to poorer-quality care. Rosa et al (2010) surveyed 112 primary caregivers, investigating socio-demographic variables, actual hours of care and burden indicators measured by the Caregiver Burden Inventory (CBI). The majority of primary

caregivers were female and married in this Italian study. They spent on average 5 hours supervising the care recipient and 4 hours staying with them. 39% did not live with the care recipient. Time caring increases with disease severity, with one study finding 50% of carers of people with late-stage dementia spending more than 10 hours a day caring (Georges et al 2008). With this burden carers have to create strategies in order to manage the situations they find themselves. Moore et al (2013) examined the strategies used by carers supporting someone with high levels of behavioural and psychological symptoms of dementia. In their interview data recreation, physical activity and household chores were common strategies utilised by carers, as was psychotropic medication (although there were concerns related to both effectiveness and side effects). Carers were involved in identifying triggers to behaviours and were sometimes involved in restraining or treating the person with dementia in a paternalistic manner. Proactively attempting to reduce stress or overstimulation, validation of the person living with dementia and diversion tactics were other strategies often used to manage the situation. Generally, the acceptance of symptoms and the maintenance of a flexible approach were required of caregivers in order to manage day-to-day living.

Sense of coherence (SOC) explains life orientation as a capability to comprehend a situation and the capacity to use available resources (Eriksson 2007). Orgeta & Sterzo (2013) examined SOC within family carers of people with dementia and, in their survey approach, identified high levels of stress as well as anxiety and depression within this population, and this was strongly related to SOC experienced by carers. Greater stress related to caregiving is likely to hamper the use of effective problem-solving strategies and therefore influence family carers. Though this was a non-representative sample (since most carers and patients

were well educated in this study), it does resonant was other evidence from Andren and Elmstahl (2008), who also measured SOC and found that the relation between burden and perceived health was influenced by coping strategy. Valimaki et al (2014) conducted a longitudinal study using a subsample of 241 patients and caregiver dyads to measure the determinants of a decreasing SOC in spousal caregivers. In their survey work to investigate the change in the trajectory of SOC and the associated factors they showed that spousal caregivers' SOC decreases during caregiving, especially if a spouse caregiver already has depressive symptoms at baseline. Independent of pre-existing depression, female gender, caregiver's age and cognitive performance have an influence on change of SOC at follow-up. Bruvik et al (2013) measured the locus of control (LoC) and the burden of care on family carers. They identified that LoC was the most important factor associated with carer burden and was associated with use of hours per day to assist the care recipient with dementia. Those carers who felt that what was happening to them was the consequence of their own actions were less burdened than carers not expecting control.

In a systematic review by Schoenmakers et al (2010) examining factors of caregiving on older caregivers, depression was a feature in one in three of caregivers and it occurs more frequently in those who care for patients with dementia than in caregivers of patients with other chronic illnesses. This burden can be associated with changing role patterns, the continuous nature of caregiving required in supporting someone living with dementia and the lack of control and uncertainty of the situation. This lack of control was also a causal link for depression in the work of D'Aoust et al (2014). Depression was more prevalent in women, with more women taking care of an ill relative as well as maintaining existing household tasks. Depression was also associated with the dependency of the person with

dementia and the psychological impact of perceiving deterioration in functional abilities.

Partners appeared more sensitive to the mental deterioration than other caregivers.

Caregiver grief at the care recipients' deterioration was also a feature of this process, with caregiver grief scores highest among carers providing support for patients with profound dementia (Warchol-Biedermann 2014). In a systematic review by Chan et al (2013) the prevalence of anticipatory grief ranged between 47% and 71%, with depression strongly associated with increasing anticipatory grief.

2.8.2 Complexities of carer role

Although the literature related to care burden is extensive, there are positive aspects of caregiving in dementia, and Lloyd et al (2016) undertook a critical review of the qualitative literature examining this. They suggest that the quantitative methodologies are often used to explore and describe what is ultimately a subjective experience, and the nuances of the caregiving experience are not readily captured. Within their qualitative review in most studies there was a sense of role satisfaction for carers when carrying out caregiving duties (although there was variation in the quality of the satisfaction experienced). Some carers took it as a job to be done without emotionally linking this to the familial relationship whilst others gained deeper satisfaction and a pride in caregiving. This was often precipitated upon the quality of the previous relationship with the care recipient. There are also elements of emotional rewards and a sense of personal growth such as increased patience, self-respect and self-awareness. Other more positive aspects were a sense of competency and mastery in the role of caregiving in terms of learning new skills and, particularly within the American literature, an increase in faith and spiritual growth. The inevitable dependency was seen by some carers as bringing them closer together emotionally, and this was often underpinned

by a sense of duty and reciprocity in which the carer was giving back to their loved one. This was particularly evident within Black and minority ethnic carers who perceived dementia as a natural part of ageing and their caregiving role as a natural progression in their life and a way of repaying the care they had received previously (Johl et al 2016). Approaches that appear most effective in exploring the underlying complexities of carer coping are those that take a more balanced, nuanced approach to understanding the carer experience than simply focusing on carer burden. This work highlights the importance of carers' meaning-making and psycho-social and emotional skills and knowledge resources in shaping the carer experience and ability to cope. Shim et al (2012) undertook a comparative qualitative analysis of stories of spousal caregivers of people with dementia and identified three groups of caregivers, labelling them as negative, ambivalent and positive on the basis of on the perceived level of positivity or negativity of their respective experiences. They distinguished certain characteristics within the carer profiles that explain how some caregivers were able to perceive positivity and meaning in caring for their spouses with dementia. This was often associated with a high level of empathy and compassion towards their spouses and was more focused on the needs or integrity of their spouses rather than their own. An ongoing emotional connection was integral to this process, involving attentiveness to body language, mood and feeling. Egdell et al (2010) examine how informal carers navigate support in dementia care, and this study highlights the importance of networks in carer experience. The researchers use vignettes to illicit responses from carers and suggest carers do not have pre-existing networks to automatically access but rather they position themselves both at micro- and macro-level in order to extend and negotiate caregiving. This is often done through tensions regarding home care as this becomes the site of long-term care and issues such as 'wandering'. The meaning of quality care and risk management have to be navigated

through the blurred public/private boundary of the home environment. Shim et al (2013) explored the meaning in caring for a spouse with dementia, and they found all the caregivers of this study were determined to live the values they believed in and to apply them to their relationship(s). Each caregiver appeared to derive strength from their experience, education, career or upbringing conceptualising the difficulties of caring as a challenge rather than burden. This often involved actively seeking resources to support caregiving, maintaining a positive attitude whilst accepting the reality of the situation.

Egdell (2013) explored the situated nature of becoming a carer and the complex nature of why a person becomes a carer. In her interview data there were three key issues that influenced who provides care and why; relationships, geography and employment. For adult-child carers this may be out of a sense of reciprocity since they looked after a parent through older age, but providing intimate care provision in the adult-child and parent relationship represented a challenging change in the family dynamic. Individual siblings may take on the caregiver role because of geography or gender assumptions, or because no one else took responsibility. Employment needs meant those carers who were not in employment or had an established career pathway were expected to provide care. This often meant those with least financial resources took on the demands of care and highlights the lower social value placed on care provision in relation to paid employment. Putting limits on the amount of care they would provide was a process full of ambiguities and contradictions for all the adult-child and sibling carers in this study. The spouse carers negotiated the boundaries of the caring role in different ways by identifying when, where and from whom they expected support. There were, however, uninformed choices from carers because of inadequate information about available formal service provision. The

implication of this is that some carers may be providing levels of support at home that they are uncomfortable with since they do not know they can ask for support. Carers may become tied to the home and neighbourhood and the day-to-day realities of care provision may remain hidden.

Camden et al (2011) reported part of the findings of a larger longitudinal study investigating the mental health of carers. They examined the reasons why family members become carers, and from the interview data practical reasons were posited as the main factors, such as living nearest to the person with dementia or being the only person available. The 'positive' reasons cited included having a close relationship with the care recipient, being the most appropriate person to take the caring role and they wanted to do so. More 'negative' reasons include others unwilling to help, they were not suited to caring and did not have a good relationship with the care recipient. The researchers suggest that health professionals should question how the primary carer came to be in this role but, as Egde (2013) has indicated, this is often haphazard and not a rational organised decision. Campbell et al (2008) used a cross-sectional survey design to determine the burden of carers for someone with dementia and identified that it was not the 'objective' load from the patient that directly determines burden levels but the 'subjective' interpretation by the carer and the subsequent coping of the carer. 'Role captivity' within carer perceptions can cause an erosion of a sense of self and potential resentment to the recipient of care. This was particularly evident in the presence of carer depression, an issue affecting quality of life generally for carers of people living with dementia (Bruvik et al 2012). The results show that carers who feel they have low levels of intimacy, communication, affection and compatibility had higher levels of burden. Wang et al (2014) also identified the increased

prevalence of chronic illnesses in caregivers of persons with dementia, with older female spouse caregivers having the greater risk of chronic illness and experiencing greater burden and strain from caregiving. Carpentier et al (2010) used a life course perspective to study the entry into the illness trajectory from a carer's perspective and they identified 5 types, including families' past experiences in which the onset of dementia is integrated into a trajectory of care for physical or mental problems that are already well under way. This group is health literate and can navigate formalised care with the illness diagnosed relatively quickly. The illness is often at an advanced stage and carer burden is often high. The second type of entry is characterised by isolation, with little family involvement in care. The caregiver's social network is often small and a significant event usually highlights the deterioration in health status. The third type of entry is based on the organisational effects such as visits to a GP, and this situation is characterised by negligible social interactions. Type 4 is marked by the slow progression of the disease and a cohesion in the help-seeking actions of the person's wider network, while type 5 a long wait before the diagnosis with disruptions to this process. This study ties together family history, linked lives, human agency and organisational effects that may affect entry into the illness trajectory.

Arber & Venn (2011) highlight caregiving at night and the surveillance and monitoring required at night in order to assess risk and make sure the person living with dementia is safe. This is largely an invisible task, although adversely affecting the carer's sleep. Within the sample related to dementia, Arber & Venn (2011) highlight that wandering and shouting were a source of anxiety, and a key factor was whether the carer could fall asleep easily after the disruption. This was less likely if disruption caused stress or anxiety or the carer had worries about the care recipient that prevented or delayed a return to sleep. The

anticipation of night-time monitoring and surveillance also delayed restorative sleep for carers. McLennon et al (2011) presented a cross-sectional, descriptive study of 84 community-residing spouse caregivers, also exploring the finding of 'meaning' as a mediator of burden on the health of caregivers of spouses with dementia. They identified that caregiver burden had an indirect effect on caregiver mental health that was partially mediated by finding meaning and therefore underscored the importance that this may have in acting as a buffer of the burden of caregiving. Daly et al (2012) used a grounded theory approach to explore how informal carers of people with dementia manage alterations to relationships and their social world and generate a theory of 'sustaining place' which was linked to a person's social identity and their interpretation of situatedness experienced across all aspects of living. This involves nurturing relationships and attempting to include people living with dementia in the face of stigma. Quinn et al (2009) undertook a systematic review on the impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia and identified that the care recipients' needs for help with activities of daily living and level of behavioural problems were found to influence the caregiver's perceptions of relationship quality.

2.8.3 Carer concerns

Nichols et al (2009) examined dementia caregivers' most pressing concerns. From their survey of 165 caregivers, depressed caregivers requested more information about depression, adult day care, grief, caregiver feelings and relaxation. Caregivers of individuals with mild dementia requested more information on confusion, driving, patient depression, shadowing, telling the patient and others, grief and depression. These issues were similar across race, gender and relationship although carer depression and the severity of cognitive

impairment of the care recipient affected the carers' stress and coping needs. Helmes & Pachana (2014) examine carer levels of concern on driving and other activities and they use data from the three waves of the Canadian Study of Health and Aging (CSHA) which investigated the concerns of the informants sampled about various activities in those they reported on. These results were based on a sample of 2780 participants over 65 years. The primary concerns of carers were for memory lapses, while activities with significant risks, notably driving, were seen by fewer than 1% of carer informants as the primary concern. The proportions of informants concerned about cooking, driving and managing finances shifted over time at different rates.

2.8.4 Decision-making

Lord et al (2015) conducted a systematic review examining barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia, and identified that resistance from the care recipient to accessing services, care and treatment was a common feature from the evidence base. Carers often felt excluded from decisions made in hospital and those who felt unsupported by professionals found decision-making more difficult. Through collaboration with trusted and informed healthcare staff the decision-making process was better facilitated and this was further enhanced by giving the opportunity for carers to talk and seek reassurances after the decision(s) had been made. Miller et al (2016) also conducted a review specifically examining shared decision-making in dementia in relation to family or carer involvement. The most likely scenario for persons with mild dementia was a shared decision-making process and a consensus decision with a family carer. For those living with moderate dementia, family carers are more likely to either check-in before making final decisions or make the final decision alone. Family carers who

perceive “cognitive overload” in their care recipient may deliberately limit or restrict the number of options offered, although the accuracy of the family carer’s perception of the values and preferences of the person with dementia was associated with greater involvement of persons with dementia in decision-making. Livingston et al (2010) examined family carers’ decision-making for people who lack capacity through focus groups and individual interviews. Barriers to decision-making by carers included the denial of the problem and rejection of help from the person with dementia, and from health professionals the failure to recognise the problems, the subsequent late diagnosis and the timing and quantity of information given. Claims to confidentiality and data protection as well as bureaucracy and rigidity also meant that carers’ ability to make decisions was sometimes compromised. These issues had a psychological cost for carers, often centring on role conflict, carer guilt and family conflict with rigidity in the face of changed circumstances. Areas that facilitated decision-making process for carers were the care recipients’ deference to authority and from health professionals a willingness to suggest interventions to facilitate agreement, the quality and timing of information and inclusion of the person with dementia in asking permission to give information to carers. The access to legal advice in cases involving lack of capacity was also viewed as helpful. Coping strategies that supported carer decision-making capacity included the carer accompanying the patient in consultations, social support, resources and family cohesion, and allowing services to develop slowly and using them to optimise independence. Knowing what the patient wanted when they were competent and opportunities to share the decision-making process were also important. Samsi & Manthorpe (2013) explored decision-making in a qualitative, longitudinally designed study with 4 time points of data collection from month(s) 0-1, then 4-5, 8-9 and 12-13. Three underlying principles framed the decision-making process,

including the importance of maintaining autonomy over decisions, and adoption of a 'decision-specific' approach for most people with dementia and their carers based in everyday conversations. Thirdly, any decision made on behalf of someone else was reported as being in his or her best interests. There was a continuum with a gradual transition from supported decision-making to substitute decision-making.

2.8.5 Carers' interactions and engagement with service providers

Service provision was a key area within the literature, and Morgan et al (2014) explored caregivers' hopes and expectations following referral to a memory clinic (within a rural setting). A feature of their experiences was the fragmented nature of formalised pathways of care and the length of time taken to reach this point, typically two years from first noticing signs and symptoms of cognitive difficulties. This may reflect issues related to GPs' willingness to respond to carer concerns (Robinson et al 2009). Carers appeared pivotal in navigating healthcare systems and addressing obstacles to effective care management. There was uncertainty as to what was happening and what to do, leading to motivation for a diagnosis. Informal carers needed to become proactive and assertive in their engagement with GPs, and this reflects other evidence (Leung et al 2011, Hinton et al 2004). Importantly Morgan et al (2014) suggest that families wait to access treatments and plan for the future on the basis of a diagnosis and often have a sense of relief post-diagnosis since the speculation has ended and they can move on. There was relief, validation and greater awareness of resources and services and this was often in tandem with the anticipation of access to treatment (this reflects the work of Cahill et al; 2008). Ducharme et al (2011) examined the transitional role to caregiving following diagnostic disclosure of Alzheimer's disease and compared these characteristics by caregiver gender and kinship tie to the

person with dementia. They identified no meaningful emotional support from friends and family within this process and a significant absence of informational and service provider support. This can be due to the mild nature of cognitive impairments on initial diagnosis and the inability of friends and family to know how to support or respond in the face of a dementia diagnosis. There was a clear difficulty in both awareness of and navigating through the formal services available. Any information given at the point of diagnosis is difficult for carers to retain owing to the emotionally charged nature of this clinical encounter (Carpenter & Dave 2004). Ducharme et al (2014) also found women carers to experience more psychological distress than men and that spouse were less able to respond to the disruptive behaviours of their relative. This latter point may be related to living with the person with dementia making respite difficult. A review by Robinson et al (2011) examining individual and family experiences of receiving a diagnosis indicated that a majority of people with dementia support open disclosure with no significant longer-term psychological ill-health (although reports of family carers may contradict this). Family carers need to come to terms with the role change and responsibility for supporting the person with dementia and the emotional difficulties this can entail.

Orpin et al (2014) examine sources of support for rural dementia carers and, counter-intuitively, did not find a lack of available formal services an issue. They did have limited GP alternatives compared to an urban context but the researchers rather found the requirement to examine and acknowledge the emotionally challenging, all-consuming and intensely private nature of the primary caring experience and responsibility of key importance. There was a clear reluctance to entrust any of their assumed responsibility as primary carer to others and then only to a select number of trusted, almost exclusively

professional providers. There was a clear sense of responsibility for carers, which was foundational and fundamental in nature. This led to hyper-vigilance in maintaining standards of care and of gatekeeping formal carers to ensure they could be trusted to deliver high-quality care. This gatekeeping also appeared to exclude non-professionals such as family and friends from the full burden of care. Guilt was a feature of allowing formal carer services regardless of carers' individual need. There was also confusion over service providers, especially since the fragmentation of service meant multiple home visits from different formal carers. In-home respite was more accepted than out-of-home respite since out-of-home respite was more difficult to monitor in terms of quality of care. The researchers suggest carers are not so much in need of care but rather a supportive partnership with service providers is a more meaningful and fruitful avenue to conceptualise the relationship. Olazaran Rodriguez et al (2012) used a survey approach to a population of carers who support someone living with dementia who were referred to primary care from general neurology clinics in Spain. Demographically their sample indicated that the majority of patients were older women cared for by their daughters. Few accessed day care services or participated in a specific training or workshop programme. Gage et al (2014) undertook a cohort study examining service utilisation and family support of people with dementia. Their data were based on 109 people with dementia and carers who had entered hospital from their own homes. By 12 months, 40 (36.7%) had died and 85% of the survivors were living in care homes. Those living alone had larger care support packages than those living with others. Median caring time for co-resident carers was 400 min/day and 10 h/week for non-co-resident carers. Carer stress reduced significantly after the person with dementia entered a care home. Alwin et al's (2010) study used a survey design to examine the perceived importance of services received from caregivers of people with dementia and its

association with experienced negative impact. This study was the Swedish part of a wider European EUROFAMCARE multi-site study. Information concerning the disease and available support were perceived as very important as well as the opportunity to discuss the issues pertinent to them as a carer. Two groups were distinguished by significance of negative impact (NI) due to the caregiver situation, the higher NI group and lower NI group were based on the NI scale from the COPE index (Balducci et al 2008). A higher proportion of caregivers in the lower NI group as compared to the higher NI group had received support or services making it possible for them to spend more time with their family. Data indicated one significant difference between the groups: a higher proportion of caregivers in the higher NI group wanted the opportunity to enjoy activities outside of caring, suggesting that the burden of care prevented broader engagement outside the home.

Sometimes societal pressure and cultural expectations meant female carers were reluctant to access services, Toepfer et al (2014) took a social representational approach to explore the processes of anchoring in the understanding of 29 carers who were wives and daughters caring for a relative with dementia. They also examined 43 newspaper articles pertinent to the research objective. Their findings suggest that social representations of childcare and the good mother served as a prevalent source domain to embed dementia caregiving. This was also the case for the newspaper articles. The behaviours and activities of people with dementia were predominantly described as resembling those of children. The shared attributes that make both childcare and dementia care comparable are the care recipient's fixation on the primary carer, the need for the responsibility of caring to take precedence over all other interests and the caregiver's natural aptitude for caring. These attributes may inhibit female carer use of formalised services.

Rural communities were affected by service provision. Innes et al (2011) conducted a systematic review to further explore informal caregiving of people with dementia in rural and remote settings. They found relatively sparse evidence in relation to carer experience, with low use of formal support services and clear gaps in service provision.

Recommendations focused on increasing public awareness of dementia and increasing the availability and accessibility of formal services as well as taking a more person-centred approach that takes account of cultural diversity. The use of care management and more effective service integration were also areas of importance.

2.8.6 Respite care

Respite care is an important area of dementia care but the uptake of formal in-home and community care services is lower among the carers of people with dementia than for other conditions associated with ageing (Bakker et al 2013, Lloyd & Stirling 2011). Maayan et al (2014) conducted a Cochrane review on respite care for people with dementia and their carers, and, of the four trials included, the evidence was rated as very low. Re-analysis of outcomes using data from the published studies found no significant effects of respite care compared to no respite care on any caregiver variable. Robinson et al (2012) examined issues surrounding seeking respite through telephone interviewing of 10 carers whose family member refused to attend day respite care and 7 with carers whose family member did attend day respite care. The researchers identified five themes, the first focusing on obtaining appropriate information about accessing day respite care. For some the process was confusing, while for others the sheer volume of information proved overwhelming. There were also issues of who to contact within the large array of health professionals in the aged-care sector. The 'maze of information' was difficult to navigate. The second theme

related to 'feeling unsafe as a barrier to attending' and this was often related to the potential for embarrassment or leaving the home environment with the security and familiarity this entailed. The third theme, 'reacting to refusal to attend', focused on carers' reactions to this decision, which ranged from acceptance to frustration and despair. Most carers accepted the decision of the care recipient and did not blame non-attendance on the respite centres, indicating that nothing the day centre could do would alter the decision not to attend. The fourth theme, 'helping to ease the transition to day respite care', centred on strategies to promote feelings of safety and security with the care recipient. The final theme, 'benefits of attending', highlighted the perceived benefits of carers who had a family member attend day respite. Neville et al (2015) conducted a literature review on the use of respite by carers and found self-permission to utilise respite can be a significant barrier. Guilt from perceptions of abandonment, duty and social bonds made respite a challenging option. There was also an issue of the quality of respite care and whether this would be maintained within the care home. Phillipson et al (2013) conducted a small convenience sample surveying help-seeking carers of people with dementia who were living in the community. In particular the researchers investigate care beliefs regarding out-of-home respite services and why some carers do not utilise them. Of the 152 participants (response rate 51.7%), negative service beliefs are the strongest correlates with the non-use of out-of-home respite services. Over half of carers did not use day care centre services and almost two-thirds did not use residential respite care. This may represent concerns about the quality of care or staffing levels. In further work examining the implications for policy and practice Phillipson et al (2014) undertook a narrative synthesis of peer-reviewed literature to facilitate the mapping of factors which influence the respite service use behaviours of carers. Demographic variables within carers who do not utilise respite services appear to

differ by service type. For day- care non-users were more likely to be spousal carers, for in-home services older women were more associated with non-use. Carer health and carer attitudes also played a significant part in non-use of respite services, with stigma a potential issue. There was also a necessity to understand the service system and be able to navigate this, or else carers are not likely to use services. This goes beyond mere information-giving about available services carers can access.

McPherson et al (2014) used a qualitative descriptive design to identify what participants thought were key components of services that worked well. Data were analysed using conventional content analysis, and 4 themes were generated, including 'quality of care for the care recipient' in which 'real' caring was distinguished and identified as a key indicator of quality by informal carers. Real caring was characterised by trust, services and staff responding to need, an engagement in meaningful activities founded on compassion and humanity rather than financial constraints. The second theme related to knowledge exchange and a particular emphasis on acknowledging and respecting the carer's expertise. Knowledge exchange that valued the carer's input was perceived as important. The third theme centred on the concept of 'one size does not fit all', and carers highlighted the contextual nature of care, with service providers minimising the everyday events and environments when assessing need. The fourth theme, 'a constant struggle', encompassed informal carers' experience that formal services created, rather than alleviating, burden by their having to 'fight' for services. These findings were also reflected in the work of Peel and Harding (2013), who found services a 'maze' to navigate for carers, with limited service provision, and military metaphors used to describe the 'battle' with formal service providers a common theme for carers of people living with dementia. Singh et al (2014) carried out a

study exploring dementia care and the intersecting of family and formal care. The issues generated centred on interaction with medical and aged-care services and in particular the significance of delays in initial diagnosis, the lack of information for non-medical support services and a lack of understanding of the needs of informal carers by service providers. The second major theme was the impediments and enablers at the level of formal community services. The issues generated from this theme were both the quality of in-home and day care services and the appropriate and accessible opportunities for carer participation in formal services.

Gorska et al (2013) examined service-related needs of people with dementia from a carer's and service user's perspective and identified the significance of early diagnosis for timely access to appropriate services and medication. The carers within this study were concerned that the diagnostic procedures were based mainly on the assessment of cognitive abilities, did not consider the person's daily functioning, and were distressing for the person with dementia. This was compounded by inadequate explanations as to the purpose of repeated testing and insensitive communication by clinical staff. Post-diagnostic support was poorly co-ordinated, with many agencies and departments for carers to navigate and poor inter-professional communication making this process more challenging. There were issues with continuity of care, with carers feeling that failure to ensure continuity of personnel involved caused distress and anxiety for people living with dementia and did not allow for the building of interpersonal relationships within care. Access to non-pharmacological interventions to support identity and social engagement was seen as an essential element of high-quality care. Stirling et al (2010) used a mixed-method exploratory approach to measure dementia carers' unmet need for services. They recruited a small convenience

sample of 20 carers, and a key implication generated from the data was that perceived needs expressed by carers of people with dementia are an important indicator of service need. The causes of burden in carers are often multi-factorial and not just based on the needs of the care recipient. Other life circumstances may mean that even modest care recipient needs may cause excessive carer stress. As Stirling et al (2010) suggest, “the significant correlation between our carers’ mental health status and their stated need for more services suggests that felt need should be given greater priority over normative need in assessing service needs for carers of people with dementia” (p7).

Graessel et al (2011) analysed the predictors for utilisation of home nursing or home help in dementia cases (in a German context) and explored family caregivers’ views on the quality of those two services. 41% of carers said they needed home nursing urgently or very urgently compared to 27% who said they needed home help urgently or very urgently. The chances of using home nursing as well as home help increase significantly when the person with dementia becomes older and for home nursing when the caregiver is younger. There was generally a lack of adequate information about the availability of such formal care services. Sutcliffe et al (2015) undertook focus groups examining experiences of dementia care and services. These data suggest that people with dementia and carers had issues with late diagnosis and poor communication and needed readily accessible breaks, consistent and flexible services and respite care in a place that carer and care recipient were comfortable with. Training was seen as an important area to improve quality of care, as were a single point of contact and continuity of care. The timeliness of appropriate information was also a significant issue for participants.

2.8.7 Living and caring for someone living with dementia: acute services

About 40% of people over the age of 65 in general hospitals have delirium, dementia or both together (Goldberg et al 2012), with patients living with dementia being significantly older and having poorer functional ability than patients without dementia (Travers et al 2013). There is also the associated issue of unassessed or unidentified patients with cognitive impairment who are admitted to an acute environment (Joray et al 2004, Soderqvist et al 2006, Nilsson et al 2012). This would suggest that patients with cognitive impairments may have specific needs that are not addressed since no screening has been undertaken. There are still a number of issues even when a confirmed diagnosis has been made. Clissett et al (2013) examined person-centred care in a hospital setting through non-participant observation using Kitwood's five dimensions of personhood as a priori framework. Issues of 'attachment' and connecting with people living with dementia were a key finding and this was founded on continuity of staff, the communication skills of the individual members of staff and whether they recognised the relationships that matter to the person with dementia. This affirms the work of Edvardsson et al (2010) who assert that for people with dementia it may be more important that the experience of a task is positive than that it is completed efficiently. Clissett et al (2013) also identify that inclusive practice is an important area with positive outcomes if healthcare staff are taking opportunities to engage people with dementia. This was often opportunistic in nature and incorporated in routine caring tasks. Maintaining identity, such as using preferred name and an empathetic engagement, supported personhood, with missed opportunities often involving not using personal belongings and no 'personalisation' of the bed environment. Norman (2006) again affirms the importance of nurses' perceptions of people living with dementia which can lead to the constraint or realisation of a person's portrayal of self. Jurgens et al (2012) report an ethnographic study of older people with mental health problems admitted to medical or

trauma orthopaedic wards as an emergency and their family carers. In their interview data the admission process was perceived by carers as a 'crisis' point independent of the competence and quality of the healthcare professional response. Some carers, on the basis of previous experience, sought to delay admission, concerned that the process would be more harmful than the physical illness. For carers the ward environment experience was variable, with concerns relating to symptoms and their cause, resisting early discharge, bed moves and lack of communication with professionals. Hospital care was often blamed for a deterioration in the health of the person with dementia. There appeared a failure to address particular needs of the person with dementia or to seek information from family. Carers' measure(s) of quality appeared to be grounded in food, hydration, maintaining safety, showing warmth towards patient and family carer, using appropriate approaches to caring for a confused person and suitable medical care. Measures of poor care focused on soiled sheets, insertion of urinary catheters, physical isolation and loneliness. Family carers thought staff were most concerned with delivering medical treatment and task-orientated care. In terms of discharge, deliberation and planning were crucial for a successful discharge process. Jurgens et al (2012) propose a 'cycle of discontent' in which events and expectations lead to bewilderment and suspicion. This in turn leads to hyper-vigilant monitoring and then anger, challenging of care, conflict and potential withdrawal.

Moyle et al (2010) highlight the challenges of health professionals in supporting people living with dementia in an acute environment, in particular, the lack of available time, the acute care environment itself and the focus on safety became key for staff at all levels. This latter point led to excessive and unnatural monitoring of patients with little emphasis on meaningful engagement or interaction. Participants suggested resources were allocated on

the basis of the level of risk rather than need. “Specialling” was the most common form of care management, in which a member of staff was allocated to observe the patient for the whole shift. Whilst one-to-one care could offer therapeutic outcomes in terms of engagement and assessment, Moyles et al (2010) found very little meaningful interaction, with task-orientated care predominating. Nursing staff described this role as akin to ‘babysitting’. Nilsson et al (2012) used a cross-sectional survey design to assess staff attitudes to older patients with cognitive impairment and identified that it was often young healthcare support workers who appeared to have negative attitudes towards people with cognitive impairment. They suggest that it is often this group that is involved in personal care such as “specialling” and that challenging behaviour often occurs in relation to intimate bodily care (Isaksson et al 2011). This could lead to healthcare support workers being at greater exposure to challenging behaviours, and their attitudes may express the demanding care situations that arise in supporting those patients who are cognitively impaired within the acute care environment. Other issues which were associated with negative attitudes included higher perceived prevalence of cognitively impaired patients and the perceived higher strain of caring for this group of patients.

The clinical environment in acute care has been given consideration within the literature, and, when ward design is focused on surveillance, security and infection control the result can be a very noisy environment with lots of open spaces, features not ideal for people with dementia (Barnes 2006; Zuidema et al 2009; Digby & Bloomer 2014). Cowdell (2010) undertook an ethnographic approach using observation and interviews, she found that interactions were dominated by the delivery of essential physical care, and that communicating effectively with patients living with dementia was poor, leading to

uncertainty. The quality of care delivery was mixed, with some episodes representing a 'new culture' within dementia care; the attempt to maintain a person-centred approach and avoid the 'malignant social psychology' identified by Kitwood (1997). Other episodes appeared to represent 'old culture' and were based on the bio-medical model with an underlying philosophy of 'no cure, no hope'. People with dementia became objects of care with little social engagement by healthcare staff.

Dewing & Dijk (2014) undertook a literature review of older people with dementia in general hospitals and identified a conflict of priorities between acute care for existing co-morbidities and person-centred dementia care. Hospitalisation was not seen as respite for carers but rather added to carers' physical and emotional exhaustion regardless of the quality of care received in hospital. There appeared to be inadequate training in managing people living with dementia. There is also evidence that specialist posts such as clinical nurse specialists or dedicated units can enhance quality of care and ameliorate the adverse consequences of hospitalisation (although they do not significantly impact on reducing length of stay or the cost of care). Bradshaw et al (2013) explored carers for older people with co-morbid cognitive impairment in general hospital and found strain and psychological distress a common feature, with differences based on living arrangements. Carers giving community support were under greater strain than carers of people living with dementia in care homes. There was no difference in strain between non-resident and co-resident carers although co-residents had poorer physical health. Issues such as behavioural symptoms, faecal incontinence and delirium were associated with greater distress and strain. Bauer et al (2011a, 2011b) used a qualitative, constructivist approach, interviewing 25 participants to examine hospital discharge as experienced by family carers of people with dementia. They

identified a lack of information on the patient's condition, a need for education about ongoing care requirements including medications, symptom monitoring and management, greater psychological support and assistance in managing and negotiating care services. There was often a perception from carers that their knowledge of the care recipient was undervalued and the nature of the care delivery by hospital staff was a key driver in preparation for discharge. Jamieson et al (2016) undertook 30 interviews with carers and validated emerging themes in one focus group. The findings suggest there is a paradox in hospital for carers, with some carers asked by staff to be present as a familiar person to support essential care requirements, yet concurrently these carers felt ignored by staff. The transition to home was difficult due to inconsistent and often non-existent discharge planning, with carers feeling judged by some health providers with increased tiredness from hospital vigils to support their care recipient. The complexity of service boundaries was difficult for carers to navigate. At home social support was highly valued and this was usually via informal networks. While their care recipient was in hospital carers were concerned about unmet care needs, particularly associated with communication and physical care, with many carers feeling a need to be present in hospital to safeguard their loved ones. Bloomer et al (2016) interviewed 20 carers of people with dementia who transitioned through acute hospital care to rehabilitation with a view to placement in a residential care setting (in Australia). They highlight that the emotional health of carers is not generally supported by the health service when a person with dementia transitions through the health system. The carers who coped well with the experience tended to be more pragmatic or had good social support from family and friends. The carers were often used to making the decisions and doing most of the cognitive work for the patients and they worried that the patients might be misunderstood or neglected without the carer present to

speak for them. Timmons et al (2016) conducted a national audit of 35 acute hospitals, collecting data on care from admission to discharge using a retrospective chart review, hospital organisation interview with senior management and ward-level organisation interviews with ward managers. A standardised assessment of functioning was carried out on only 36% of patients with dementia, with pain assessment also poor. Moyle et al (2016) examined family involvement in care of people with dementia in acute care. In this qualitative approach carers reported that their main role was to provide emotional and, to a lesser extent, physical support. They would talk, take their loved one for walks and undertake activities that demonstrated caring. Information was a key concern, with carers needing to be kept updated in regard to the person's medical condition and their plan of care and discharge. Access to medical staff appeared limited and when it occurred the terminology used was difficult to comprehend. The hospital environment was confusing and overwhelming and carers wanted to be part of the team but were frequently excluded.

2.9 Stigma and dementia

For this section I used a critical review (Grant and Booth 2009) rather than systematic literature review. This goes beyond mere description to include a degree of analysis and conceptual innovation. It seeks to identify the most significant items in the field and is more conceptual and chronological. I have therefore traced the concept of stigma back to the work of Goffman and then applied this to the literature related to stigma and dementia. The term "Alzheimer's disease" has been shown to be more associated with an initial negative response than other causes of memory loss and dementia, with persons with dementia and carers both reporting concerns around stigmatisation associated with the term (Derksen et al 2005; 2006, Aminzadeh et al 2007, Langdon et al 2007). Social constructions of individuals

with dementia as 'the living dead' (Aquilina and Hughes 2006) and 'zombies' (Behuniak 2011) marginalise people with dementia. This fear and stigma related to dementia was commonly expressed in people living with mild cognitive impairment who wished to avoid the 'death sentence' diagnosis of Alzheimer's (Beard & Neary 2013). Within both the scientific community and media representations the depictions of dementia typically include 'narratives of tragedy' (Basting 2009) with a focus on the caregiver's plight rather than on the person with dementia. The use of military metaphors when discussing dementia has also increased in medical literature and mainstream media (Lane et al 2013). The usefulness of such metaphors has been questioned since the work of Sontag (1978) and particularly in relation to cancer care. It can maintain pressure to be brave and leave the person isolated from family and friends (Witham et al 2013). If the patient has not 'defeated' the disease then are they a failure? The burden of dementia is often situated within other chronic conditions, making metaphors about 'fighting' particularly unhelpful. The framing of memory loss has typically been through a biomedical discourse of loss (Beard & Fox 2008) with dementia characterised as the slow goodbye and leading to the destruction of self in spite of literature portraying individuals living well with dementia (Basting 2009, Beard et al 2009). People with dementia have attempted to normalise their experiences and avoid the framing of their social identity as an 'Alzheimer's patient' (Beard & Fox 2008, Beard & Neary 2013), an ascribed spoiled identity (Goffman 1963).

Sabat & Harre (1992) assert that positioning and framing people with early stage of dementia can seem to "place a person in a certain amount of jeopardy" (p 454). Within the literature the media representations of dementia have been explored by Gorp & Vercruysse (2012). They describe six frames that underpin much of the current discourse, and this

includes a dualism of mind and body, incorporating a limited interpretation of embodiment in which the 'personality' and 'self' reside in the mind and, when dementia occurs, the self diminishes. The second frame perceives dementia as an invader, a 'demon' taking over the mind, and is akin to much of the metaphoric language related to cancer. Thirdly, 'faith in science' can present people with dementia as cases and has a tendency towards biological reductionism; the fourth frame focuses on 'fear of death and degeneration' representing life as effectively over from diagnosis for the person with dementia. The fifth frame, 'reversed roles', infantilises people with dementia, seeing them as children rather than vulnerable adults. Finally, the sixth, 'No quid pro quo', involves both the loss of reciprocity and a loss of past experiences leading to a re-focus on carer loss rather than concerns of someone living with dementia. Peel (2014) identified two discourses pertinent to dementia, the first related to epidemic and the second to lifestyles. The first discourse positions itself within a biomedical framework that stresses the pathology of dementia and removes this from any perception or connection to the normal ageing process. Although public perceptions are that, memory loss is inevitable with ageing, the media coverage even related to dementia is conveyed as a health 'crisis'. The link to lifestyles can lead to an individualistic 'blaming' culture in which 'eating well' or exercise are measures in which to judge the 'moral' behaviour of older people living with memory loss.

Werner (2005) examined determinants of behavioural discrimination against persons with Alzheimer's disease, with 206 face-to-face interviews using an experimental vignette methodology varying in the severity of the disease. The results indicated that in response to the vignettes pro-social feelings were found to decrease the behavioural discrimination against the person described, whereas feelings of rejection increased the discrimination.

There was an increase in behavioural discrimination related to the severity of disease.

Werner (2006) further assessed lay persons' perceptions about the competence of a person with Alzheimer's disease, using the same sample and design as her previous work (Werner; 2005). Participants were requested to rate the competence of the person described in the vignette in the areas of driving, health decision-making, financial decisions and the performance of instrumental activities of daily living. The majority of participants perceived the person as not capable of driving, making financial decisions, riding a bus alone or preparing a cup of tea. Only two-fifths of participants, however, considered the person not capable of making healthcare decisions. Lay persons were able to make a distinction between different types of competence and this perception about competence affected greatly their behavioural discrimination towards a person with dementia.

Courtesy stigma (Goffman; 1963) has been another area of research interest in dementia care. MacRae (1999) examined the experience of courtesy stigma (Goffman 1963) among family members of persons with Alzheimer's disease. MacRae's work is informed by Blum (1991), who described two phases: the first involved the caregiver colluding with the ill family member as they co-operate in the management of information and problematic situations. The caregiver becomes a partner in passing, helping to preserve the public face of the family member and maintain the family unit. Passing involves concealment of damaging information or the management of undisclosed discrediting information (Goffman 1963: 42). There is also evidence of 'covering' (Goffman 1963): covering practices occur where the stigma becomes visible or if it is known about but attempts are made to minimise the impact. When the competence of the person with Alzheimer's diminishes and they can no longer play the collusive game, the second phase begins. In this information control

becomes secondary to the new primary concern to prevent or manage the problematic situations that arise because of the ill family member's inappropriate behaviour. MacRae (1999) found caregivers were subjected to courtesy stigma, as were other family members although a significant number of participants claimed not to have experienced stigma or were not concerned about avoiding it. This work has been explored further. Werner & Heinik (2008) explored stigma by association in Alzheimer's disease and found that the caregivers of persons with dementia perceived a minimal amount of stigma directed towards them although they clearly perceived stigma in relation to the person with dementia. This may be explained by a lack of cognitive insight in people with advancing dementia, which protects them from self-awareness regarding stigmatising aspects of functional or behavioural problems. This in itself could reduce stigma by association for caregivers. Within the study there was a high level of structural discrimination identified by participants, with cognitive functioning and behavioural problems the main factors associated with stigma by association.

Werner et al (2010) examined family stigma (in particular, adult children) in the area of Alzheimer's disease and identified three dimensions to stigma including caregivers' stigma, lay public's stigma and structural stigma. In terms of caregivers' stigma it was experienced not only as prejudice and discrimination towards the caregivers themselves for being associated with the person with dementia but also as a process imposed on their parents. Within dementia, caregivers' stigma seems to be triggered by attributions related to changes in cognition, behavioural problems or physical and functional deterioration. Physical appearance or aesthetics of the person with dementia was a cognitive attribution that was important within this research, as were shame, embarrassment and disgust as

emotional reactions of caregivers – especially since this could lead to concealment and reduced interaction between family caregivers and the person with dementia. Lay public's stigma experienced as interpersonal discrimination from other family members, friends and other persons in the community was mainly triggered by attributions associated with physical and cognitive functioning and with the physical appearance of the person with dementia. Participants described two types of fear to account for lay persons' distancing and physically avoiding the person with dementia: these were fear of getting the disease and fear of going through the same experiences. Structural stigma (related to social structures, policy, provision of services) affected access to formalised support, especially the award of long-term care benefits as well as avoidance and coercion amongst health professionals.

Corner & Bond (2004) highlighted through their qualitative study of 15 healthy older adults that some older people fear developing dementia. The participants were confused as to whether the development of dementia was normal ageing or should be attributed to disease. They perceived cognitive decline as part of older age but were fearful that this could be the precursor to developing dementia. Older people who do not have dementia avoid talking and thinking about it and did not plan for it and subsequently may be less likely to visit friends or family with dementia or those caring for them. Alzheimer's disease therefore becomes a disease of exclusion (Gubrium 1986) although contact with people living with dementia reduces stigma more than education for stigmatisers. For those stigmatised, approaches that target eliminating self-stigma may be less beneficial than interventions designed to promote disclosure (Corrigan & Fong 2014).

2.10 Implications of literature review

This literature review highlights a number of issues that have informed my research aims. Interestingly there is a paucity of research exploring the impact on carers of supporting someone with both cancer and dementia. Work by Hopkinson et al (2016) and Courtier et al (2016) have begun to explore patients' experience of cancer treatment whilst living with dementia but this does not extend to informal carers. In the associated literature of other vulnerable groups (people with cancer and either SMI, learning difficulties or dementia) there are some common threads that appear a consistent feature of patient experience. Poor communication between the health professional and the person with SMI, learning difficulties or dementia and their supporters was common, particularly in the context of conveying sensitive and complex information related to cancer treatment(although supporters were explicitly referenced only with the literature related to learning difficulties and cancer). Effective communication is central but remains challenging since complex co-morbidities can require contact with a wider social network of supporters including carers (paid and unpaid), relatives and specialist health teams. Conveying specialist information about cancer treatment or side effects and assessing patient and carer understanding can again present difficulties. This has implications for both patient safety and risk as well as compliance to treatment. Cancer therapies can be lengthy and complex and involve procedures that are psychologically stressful to people with SMI, learning difficulties and dementia. For example, radiotherapy, chemotherapy regimens and diagnostic scanning can all require a level of co-operation and adaptation not easily negotiated within these population groups. How carers navigate and manage support within this context is an important issue since, arguably, they are aware of the individual needs of the person they are supporting. The context of dementia care provides a backdrop and reveals a secondary

level of complexity to which carers are called to respond in the light of a cancer diagnosis. This often involves the challenges of accessing dementia services, the complexities of carer role, stigma and communication with both the person with dementia and any formalised care provision. Within the context of communication, decision-making becomes an important area within cancer treatment, with issues of fluctuating capacity for the person with dementia and judgements related to quality of life and treatment burden for those carers involved in supporting people with advanced dementia. The evidence would suggest that cancer treatment outcomes are poorer for people with SMI, learning difficulties and dementia, with more significant morbidity (Gupta and Lamont 2004, Sullivan and Hussain 2008, Raji et al 2008, Baillargeon et al 2011, Batty et al 2012, Chang et al 2014, Ribe et al 2016). In light of this, an exploration of carer experience may increase understanding and highlight factors that could contribute to these poorer outcomes –particularly since carer involvement and support are integral to psycho-social wellbeing and to how well patients manage their illness (Carlson et al 2001, Stenberg et al 2010). It would also further provide rich data in exploring the challenges and positioning required to support the person with dementia whilst having cancer treatment and how the interactions with health professionals support or hinder the supportive process.

Chapter 3

Methodology

3.1 Introduction

In order to address my research aims; 1) to explore the experience of carers who have supported a relative who is living with dementia and who has also received cancer treatment; 2) to use a performative narrative approach to examine the positioning of both teller and listener and the implications this suggests for carers and finally 3) to examine what this positioning means (in terms of healthcare professional response and the implications this may have in clinical practice) I have taken a qualitative approach. More specifically, I have used a performative narrative approach to examine the positioning of both teller and listener and the implications this suggests for carers. This chapter will explore the methodological challenges of a performative narrative approach and examine my use of positioning theory as a way of framing healthcare professional and carer response and the implications this may have in clinical practice. I have examined some of the ethical challenges throughout the research process, particularly associated with issues of researcher integrity and the process of ethical approval. I have further explored the issues of validity and credibility within my narrative approach as well as articulating and justifying my transcription method.

3.2 Narrative approach

As Bell (2009) comments, “narrative approaches counter traditional models of knowledge by stressing that there are multiple truths, constructed by knowers who are socially and

historically located” (p8). I used a performative narrative approach to interpret these data, and the ontological foundations to such an approach were based on a social constructivist perspective (Gergen 2009, 2011). Within this ontology, the construction of reality does not occur in an individual’s mind as a discrete faculty for knowledge generation, emotions and morality but rather within relationships. As Gergen (2009) states:

“The realities we live in are outcomes of the conversations in which we are engaged.” (p. 4)

Within this ontological stance the way in which the world is interpreted is not predicated by ‘what there is’ and the ways of explaining and describing the world are the outcomes of relationships. More positivist epistemological stances that focus on truth and objectivity in research generation are of secondary concern to the impact for cultural life that may follow any truth claim posited. The question is therefore not whether they are objectively true but what happens to our lives when these ideas enter into our relationships. A constructivist approach challenges the metaphysical assumptions that presume there is a reality out there, beyond us, independent of our actions and preceding us. It also challenges the assumption of an external reality as composed of definite forms or relations and that the world is the same everywhere (a singularity). Within this ontology there is an objection to the metaphor of the ‘mind as mirror’, that the mind is inside the head (subjective) and the world is outside (objective). This has important implications as Gergen (2011) asserts:

“This eradicates the long-standing distinction between fact & value, between is or ought.”

(p. 110)

Scientific truths can be interpreted as offshoots of communication and not observing minds. Latour & Woolgars’ (1979) ethnography of the laboratory shows that scientific knowledge is

produced by “a more or less messy set of practical contingencies” and that “in its practice science *produces* its realities as well as describing them” (p. 13). Scientific methods do not discover but enact reality. Reality is not out-there and independent, it is made and is the effect of inscription. Therefore, the constructs of ‘reality’ are fashioned by interpreting communities so issues such as objectivity and logic are deliberations not of individual minds but of community traditions. Scientific knowledge is therefore a by-product of a social process. Scientists may speak as though they are describing nature but “in practice they are more or less precariously bundling together a heterogeneous hinterland of subsequent deleted social, material and textual resources” (Law 2004, p. 121). Gergen (2009) uses Wittgenstein’s concept of language, replacing the picture metaphor of language with that of ‘the game’. When one states that an event, experiment or description is accurate or true, it is not judging it according to how well it pictures the world. The language game represents the interplay between language and action, and the meaning words possess is dependent on the requirements of that game. Wittgenstein (1958) describes the relationships of words, actions and objects as a ‘form of life’, tied to cultural traditions. Practices of language are meaningful only within relationships and these are intertwined within broader patterns of practice.

The concept of the ‘self’ as an individual discursive agent is challenged through a constructivist approach in which statements related to such utterances as “I chose” do not reflect or report the inner state of mind of the subject. This utterance is not the logical manifestation of an inner world but the meaning is grounded and contingent on its use in relationships. The formations of the self, through utterances, are constructed in performance and therefore it is not that one has thoughts, emotions or feelings but more

that one does them. These actions are relationally embedded and the performance of the self is a (re)presenting story of revealed relationships (Gergen 2011). This according to Gergen & Gergen (2011) should reconceptualise the nature of human experience from a private possession of something we have to something we do in “relational participation” (p. 380). This ontology sees, as Law (2004) comments, “the world as an unformed but generative flux of forces and relations that work to produce particular realities” (pp. 6-7). Since realities are contingent and located within a given interpretative community there are often attempts towards what Gergen (2011) describes as ‘reification’ – a concerted effort to discredit those that fail to share these local realities and values. Rather than judging scientific theory by its truth claims, an evaluation in terms of its ideological impact may be a more central issue, the effects on culture, the forms of social life which it facilitates and obliterates. The methods and approaches of natural and social science can mask the performativity explicit within this process, presenting only the product to the audience.

A fundamental tenet of a performative narrative approach is to position our lives as ‘storied’ with identity narratively constructed. There are multiple truths, constructed by tellers who are socially and historically located (Bell 2009, Reissman 2003, 2008). This approach to narrative has what Smith & Sparkes (2008) describe as a ‘thin individual’ and ‘thick social relational’ focus in relation to the self and identities. The ‘self’ is not fixed, singular and coherent but rather storied selves and narrative identities are performative and therefore multiple, changing and unfixed. Language actively constructs the self, and it is through relationships that talk becomes the ‘site’ of self and identity work through a process of co-construction between speaker and listener. In stressing this performative element within communication is not to suggest that identities are inauthentic but only to acknowledge

that they are situated and achieved within social relationships. As Riessman (2003) comments,

“Informants do not reveal an essential self as much as they perform a preferred one, selected from the multiplicity of selves or personas that individuals switch as they go about their lives.” (p. 337)

According to Mishler (1986) interviewing is a form of discourse between speakers (speech event). This requires a shared context from which the meaning is derived. An adequate understanding of interviews depends on recognising how interviewers reformulate questions and how respondents frame answers in terms of their reciprocal understanding as meanings emerge during the course of an interview. Mishler argues that language is inherently indexical and meanings in discourse are neither singular nor fixed. The interview process and the understanding of the meaning(s) generated are dependent on how questions are formulated and negotiated, and how respondents frame answers and co-create new interpretations as they unfold during the course of the interview. The assessment of meaning therefore requires analysing the interview process since it is this that grounds and constitutes meaning through discourse. This approach is appropriate for this study since the stories told by carers articulate the narratives that drive meaning and highlight how this is negotiated within an interview setting. This has subsequent implications about how interactions with health professionals are shaped and the clinical significance of such constructs.

3.3 What is narrative?

The definitions and focus of narrative inquiry is diverse, with Mattingley (1998) characterising the “eventness” (p7) of stories with their human actions and plots. She asserts that narratives are both event-centred and experience-centred. They are not primarily a recall of past events but rather she connects story and experience resulting “from the structure of action itself” (p8). Therefore one of the primary areas of exploration is how social action develops into narrative form by the actors who take up this accounting. Mattingley (1998) refers to therapeutic emplotment which encapsulates “action and experience both as personal and as something socially constructed” (p20). A plot generates meaning from a series of otherwise meaningless ‘one thing after another’ incidents and links this to a larger narrative whole. Lived experience is not linear but situated between a past and future, and this leads Mattingley to explore narrative time. For her it is events from an unfolding temporal whole: meaning is not identified at the end but rather emerges through the narrator as a whole through start, middle and end. Narrative form is underpinned by the lucidity of the characterisation of events and not just how it affirms or connects with the plot. Action and motive are integral structuring devices and often situated with desire to be in a different place. Narratives are not linear and are constituted to convey a position rather than a chronology. Narrative time is dramatic and, as with other stories, it must be a story worth hearing: the ‘tellability’ of a story is an essential element. Finally endings are uncertain, with narrative time steeped in suspense and often situated in trouble. Within current literature, there is no consensus as to the differences between stories and narratives and therefore I will use the terms interchangeably. Some writers, such as Mattingley (1998, 2010) and Frank (1995), suggest more overarching narrative genres to

which stories are culturally aligned in order to create meaning. Reissman (2003, 2008) and Bell (2009), however, avoid an explicit distinction between story and narrative and at times most narrative researchers interchange terms without an explicit delineation.

Mattingley's (1998, 2010) narrative phenomenological approach partly intersects with my own positioning since I share an understanding that:

"a narrative analysis offers a way to examine clinical life as a series of existential negotiations between clinicians and patients, ones which concern the meaning of illness, the place of therapy within an unfolding illness story and the meaning of a life which must be remade in the face of serious illness." (Mattingley 1998: p20)

Stories require action and are investigations of events but issues like motive are not to be found in attempting to guess the inner world of the narrator. To understanding motive rather requires, according to Mattingley (1998), situating the person within a cultural context and realistic narrative frame. Intentions become opaque in this specific narrative context. I situate this cultural context as generated from the interview or conversational dialogue itself since defining 'culture' a priori constitutes an unsubstantiated assertion. Rather examining the positioning and conversation within an interview will generate the ways in which practices are accounted for, constructed, negotiated and contested. In this sense I am more sceptical of grand narratives superimposed on to the situated experiences of participant conversation within an interview context. Mattingley's position resonates with Bruner's (1991) in that narrative is an account of events occurring over time and involves 'particularity', a situated event that is *"their vehicle rather than their destination. Narrative is realised through particular embodiment"* (p4). Narratives are never neutral recalls of facts and events, there are no "unsponsored texts" (Harris 1989) without

intentionality and purpose. Both Frank (2010) and Bruner (1991) emphasise that a story must be worth hearing, the tellability is important. It must be a breach or deviation from the canonical script, a presentation of a counter-narrative and the effort towards cultural legitimacy. In this way narrative, rather than referring to reality, may in fact create or constitute it.

Frank (2010) presents an approach defined as socio-narratology and he asserts that *“narratology’s basic premise is that a common, more or less implicit model of narrative explains people’s ability to understand communicative performances and types of artefacts as stories”* (p11). He views stories as either good or bad companions and as adapted, collected and (re)interpreted. They become material semiotic companions. Stories are never unique but are collected, more like “reassembled fragments on loan” (p13) but still retain the genesis of standard character, plot and style in a recognised schema (Frank’s work in this respect is similar to Taylor; 2006 and Taylor and Littleton; 2006 in acknowledging the borrowed nature of any life narrative as a resource for future talk). Drawing on the work of Latour, storytelling becomes a collective practice in which the social is constantly reassembled. Frank is particularly interested in the function of stories, what do they do and how is this enacted. This function is always dialogical, involving multiple voices in their construction and at least two but usually three in the enactment, a story, a storyteller and a listener. The analysis takes the position(s) of participants and asks what can be learnt from storytellers and “how do stories work to make characters available as generalizable resources that listeners use to engage in work on their own character” (p29). In this sense maintaining moral adequacy and accounting for the ethical self is a critical element within any narrative. Frank (2012) presents a dialogical narrative analysis in which the key drivers

to investigate include how characters are (re)presented and how this positions the listener and how story character motivations fit within the usual schema associated within communities that are receptive to such tellings. It also becomes important to examine the claims associated with character motivations and how this is operationalised and finally the need to identify the relationship to characters and non-human things that may act like characters. Frank refers to a narrative habitus in which there is a limited number of recognisable stories that a person or group can share and this will predicate the culturally appropriate reaction to such a story. Most “human responses to stories are tacit, embodied and predisposed” (Frank 2010: p54) and lead to a recognised sense of the cultural shape and outcome of the particular story generated. The interest is examining what stories are silenced by other stories and which fail to retain narrative alignment with these other stories. When does the cultural imagination fail to recognise stories as enactments of resistance and jettison the validity of this type of narrative? If stories do the work of meaning, through performing memory, what narrative(s) become meaningless and therefore not useful? Examining the available narrative resources and how these are manipulated, changed, adapted and re-told in stories are questions that narrative researchers need to examine. This process attends to our fears, dreams and desires: what are the meaning(s) of life that we create and what does it mean to live as a person?

3.4 Method

Recruitment took place at a Psycho-Oncology unit at a regional cancer centre in the North West of England. Initial negotiations took place between the unit team and myself. This included a lead psychiatrist, an occupational therapist and a mental health nurse (who was the dementia lead). Establishing relationships was important since gatekeeping could be an

issue in attempting to recruit vulnerable carers. The team supported this study and at this stage initially identified potential participants' from the previous contact that they had with carers. The team used both their existing contacts and new referrals to widen the potential participants for this study. As a Patient Identification Centre (PIC) the Psycho-Oncology team identified relevant participants. They would initially give a letter of introduction and/or further information about the study to carers who they thought were appropriate. The potential participants would complete the cut-off slip from the letter of introduction indicating interest in the study and their contact phone number. A member of the Psycho-Oncology team would collect the slip via clinic or ward-based contact (or through consent over the phone to give contact details) and then I would make contact with potential participants. Owing to difficulties in recruitment and after University ethical approval, a separate recruitment method was introduced using a modified snowballing technique to identify participants external to the NHS. The challenges in recruitment were characterised by the psycho-oncology team in two ways. Either the referrals they received were of such a significant distress and complexity that they felt the carers would be too burdened as potential participants; or the clinical situation was ambiguous because the patient's dementia was undiagnosed and therefore carers might potentially not been prepared for a dementia diagnosis at that stage.

3.4.1 Sample and participants

The inclusion criteria for carers or supporters were:

- being a carer or supporter of someone living with memory problems or dementia and diagnosed with cancer.
- being able to provide informed and written consent.

- being able to speak and understand English.
- being able to participate in an interview at a place of their choosing.

Patton (1990) has described intensity sampling as a key sampling strategy, and within this study I have attempted to select cases according to the intensity with which the interesting features, processes and experiences are given or assumed in them. This meant I worked with the gatekeepers to identify those participants who have been through the whole cancer journey with their care recipient. I have also attempted to integrate purposively maximal variation in the sample, to integrate a few cases but that are as different as possible, to disclose the range of variation and differentiation in the field. So some participants had multiple challenges whilst others had a much more positive experience. Sample size within narrative approaches remains flexible since ultimately it is a matter of judgement and experience in evaluating the quality of the data against the purpose of the research (Sandelowski 1995). The richness of the data is not based on saturation within this case based approach but rather, the sample needs to demonstrate variation of a particular social setting and of the experiences and stories arising in it. As Crouch and McKenzie (2006) assert “our respondents are “cases”, or instances of states, rather than (just) individuals who are bearers of certain designated properties (or variables). Initial recruitment was designated at 10 carers but both the practicalities of a difficult population to recruit and the richness of the data generated meant I stopped recruitment at 7 carers. Start of data collection was July 2014 and this finished in March 2015. I attempted to present the narratives of participants who had previously supported their relatives throughout treatment through to those who are presently supporting their relative. Lived experience is not linear but situated between a past and future. Narratives are never neutral

recalls of facts and events; there are no “unsponsored texts” (Harris, 1989) without intentionality and purpose, and therefore, I was interested in how participants reconstructed their narrative through the course of time. We cannot objectively know what someone’s narrative construction was at a specific time of the events. We can, however, observe how claims of identity are positioned retrospectively and examine this in relation to other participant narratives that may be interpreting events experienced more currently within the context of supporting someone living with cancer and dementia.

3.4.2 Modified snowball sampling

Snowball sampling offers benefits in reaching difficult-to-access populations. Recruitment at the Oncology centre was difficult: within my target group accessing participants was challenging due to the demands of care in supporting their care recipient throughout cancer treatment. After receiving University ethical approval I identified through academic colleagues potential participants of carers of people living with cancer and dementia. I used these gatekeepers to approach the potential participants and if they were interested I sent the information sheets to them. This could be characterised as a modified snowballing method since usually the participants within a study would identify potential participants rather than a process occurring separately. Within my context snowball sampling still falls in Patton’s (1990) definition as sampling that “identifies cases of interest from people who know people who know people, who know what cases are information-rich, that is, good examples for study, good interview subjects” (Patton 1990: 189).

3.4.3 Analysis

The pioneering work of Labov and Waletzky (1967) in using narrative analysis within their research led to a method and schema of analysing the internal structure of stories. A 'fully formed' narrative comprises six sections each containing "a group of clauses of a common functional type" (Labov 1997: 403). This included an abstract (a summary or point of a story), an orientation (to time, place, character, situations), complicating action relating to the event sequence or plot and usually centred on a crisis or turning point. There should be an evaluation in which the narrator steps out of the action to comment on meaning and resolution that establishes the outcome of the plot. Finally, a coda ends the story and brings the action back to the present. Labov and Waletzky (1967) use a remembered sequence of events as the pre-existing substructure of personal narrative. Labov (1972) has since revised the evaluation schema to assert that it is disseminated and interweaved throughout the narrative in addition to a section between complicating action and resolution schemas. There is also a suggestion that the abstract and coda are optional categories due to the irregularity of their presence within narratives whereas the complicating action becomes a foundational requirement relating to 'what happened'. This is significant because Labov's definition of a basic narrative requires "a sequence of two clauses which are temporally ordered" (1972: 360). The resolution section is required to notify to the listener the impending end of the narrative.

Labov (1997: 397) further developed his concept of narratives to include issues related to what he describes as reportability, credibility, causality and the assignment of praise and blame, viewpoint, objectivity and resolution. Reportability refers to an event that justifies

the automatic reassignment of the speaker role to the narrator, and Labov suggests that a less common reportable event has the more significant impact and gives greater justification for the automatic switch to narrator. Credibility refers to whether the listener actually believes the events described by the narrator in the form presented: the more reported the events of a narrative the more effort the narrator must devote to establishing credibility. Causality according to Labov (1997) is “that there is a proposed chain of events linking the orientation to the most reportable event” (p364), and the assignment of praise and blame has been an issue particularly salient within my interviews with the participants: Labov describes these as polarising narratives. This can be either by an antagonist breaking social convention or by what he describes as ‘integrating’ where blame is annulled or passed over. The viewpoint of a narrative clause conveys the personal experience of the narrator at a particular spatio-temporal domain. Labov asserts that there are no flashbacks in oral narratives of personal experience, a point disputed by other researchers (Norrick 2010, Och and Capps 2001). By objectivity Labov (1997) refers to an event that is known to the teller through sense experience as opposed to a subjective event which focuses on awareness via memory, emotional response or internal sensation. Lastly resolution in terms of “personal narrative is presented as a set of complicating actions that follow the most reportable event” (412).

This broadens the interpretation(s) of personal narrative from tight formal linguistic structuring and schema functions although the original group interviews based on Labov and Waletzky’s 1967 study were reported without the common components associated with dialogue in a socio-linguistic interview (Sacks et al 1974). The aspects that ground meaning and nuanced interactional speech such as silences, reported direct speech,

interruptions, foreshadowing etc. were not reported and thus present a decontextualized, generalised framework that, I would argue, fails to acknowledge the co-constructive, situated nature of personal narrative generation. Tellers re-create stories from memories of past events in a fragmented, arbitrary and selective way to suit the present context in which it is to be received. The sequential organisation in stories is not remembered as a set of ordered states and actions, as Norrick (2010) comments: “my own conversational data exhibit storytellers organizing their performances around repetition and formulaicity as much as sequence; they also illustrate more stability in evaluation and dialogue than in the sequence of events in retold stories” (p3). The stability promised by more structural approaches is always in danger of being undone, and Smith (1981) has argued that there is no basic story line that is subsequently embellished but rather an unlimited number of other narrative creations in response to a story. Our lives are not a series of basic events that are open to abstraction and assimilation. Every time we re-tell or reanimate a story, we create a new narrative. In this sense, narrative cannot ‘represent’ some reality but only re-present, providing a rupture, a destabilising of narrative order (Watson 2008).

While accepting that what was said in the interviews is important, I am positioning myself away from a more structural approach as articulated by Labov & Waletzky (1967) to a performance-based, pragmatic approach in which how the interview was performed has shaped and developed what and how the discourse unfolded. How do I position myself to the participant, how are the characters produced in the situated event of the interview and how do narrators position themselves and present that identity to the listener and themselves (Bamberg; 1997)? Therefore, in terms of my ontological position I am in agreement with Bamberg (2007) when he suggests that

“when we study narratives we are neither accessing speakers’ past experiences nor their reflections on their past experiences (and through them how they reflect their selves). Rather we study talk; talk that does not reveal immediately or directly (and potentially not even indirectly) the speaker’s internal organisation of his/her self (if there actually is such a thing). However, in and through talk, speakers establish 1) what the talk is about and simultaneously 2) the particular social interaction in the form of particular social relationships. And in the business of relating the world that is created by use of verbal means to the here and now of the interactive situation, speakers position themselves vis-a-vis the world out there and the social world here and now.” (P171)

I paid close attention to how the participants position themselves to me and also the characters they present within the narrative. How a participant constructs a character within a story and subsequently defines (or not) their relationship to that character, including the judgements and evaluations made, becomes a rhetorical device to convey how they wish to be understood. Within Mishler’s (1995) typology I positioned myself more with an interest in narrative function and the contexts and consequences of their production rather than a series of temporally ordered events. Similar to Frank (2010) it is the ‘work’ that stories do within context that is a focus of inquiry. But unlike Frank (2010) I was interested in turn-taking and how stories are co-constructed within an interaction rather than his interpretation of co-construction (generated through the interpretative framework of Bakhtin 1984) in which the focus is “hearing how multiple voices find expression within any single voice” (p35).

Within this narrative approach there are key areas of interest (Reissman 1993), including ‘attending’ to the context in which the narrative occurs, and therefore reflection on both

the location and circumstances of the interviews would be an important element of the analysis. Another salient area was the ‘telling’ of experiences that co-shape the self and what information was decided to be shared within the interview. The handling of the ‘transcription’ itself is important to support the contextualisation of the interview interaction. I have broken down the text into segments related to a sequence of episodes while retaining the thread of the whole story (Kidd & Parshall 2000). It was important to generate the detailed ‘stories’ of experience. The interview dialogue has been further analysed and interpreted by working on a set of questions, deciding which are most relevant to the interview data and iteratively revising both the questions and the understanding of the data. In particular, the questions developed by Riessman (2003; p9) cited below.

Table 3.6: Research Approach

- | |
|--|
| <ol style="list-style-type: none"> 1. Why was the narrative developed that way and told in that order? 2. In what kinds of stories does the narrator place him/herself? 3. How does he/she strategically make preferred identity claims? 4. What other identities are performed or suggested? 5. What was the response of the listener/audience and how did it influence the development of the illness narrative and interpretation of it? |
|--|

Within this process it becomes a much more case-centred approach and, as Riessman (2011) comments, *“the investigator preserves and interrogates particular instances, sequences of action, the way participants negotiate language and narrative genres in conversations and other unique aspects of a ‘case’ which could be an individual, family, community, group, organisation or other unit of social life”* (p310). Through this process theoretical concepts and observations about social processes can be made. The researcher

needs reminding of the seductive potential of a skilful storyteller and the artifice of the story generated. It is through challenging this construct that *“a good narrative analysis reaches beyond the lure and power of a good story, however, ‘transparent’ it may seem initially. Armed with an analytic stance, we disrupt common sense meanings, resist total surrender and read the texts generated from interviews differently other than narrators may have intended. In these ways we become the narrators of news texts that interpret the lives of others”* (Riessman 2012; p561-2).

Bamberg (2003) also presents a similar framework to Riessman and asks data questions related to positioning. So, for example, how are the characters positioned vis-à-vis one another within the reported event? How does the speaker position him/herself vis-à-vis the audience and how do narrators position themselves vis-à-vis themselves? McCormack (2004) provides a useful approach to analysing in-depth interview conversations and I have also used aspects of this within data analysis since it resonates with Riessman’s work. Active listening is required to specify the characters involved within the conversation and the nature and context of the main events. Further questions to address the data include: how am I positioned in relation to the participant and how does this change or fluctuate within the discourse? How do I respond emotionally and intellectually to this participant?

Following this, the narrative structure or location needs to be articulated and stories are identified from the data by recognisable boundaries, a beginning and an end. McCormack (2004) further suggests within this a narrative should possess an abstract, an evaluation generating the ‘meaning’ of how the narrator interprets the story and a series of linked events or actions which are organised chronologically or thematically in response to the question(s) of what has happened (comparable to Labov & Waletzky 1967). Language is of

central importance to me as McCormack (2004) suggests: *"it is more than a means of communication about reality. Language functions to construct individual identity"* (P225).

To this end the feature of the language need to be explored, so that what is said or unsaid and how it is said needs to be examined, since this is the creative process of identity work. Words or phrases describing relationships to the wider networks in which participants mediate and interpret themselves is of interest but I depart from McCormack in his trying to connect establishing relationships of the self to 'society'. I share Latour's (2005) hesitancy to connect short-lived interactions or new associations with the wider social forces without adequate explanation of the mediators that need establishing to make those assertions. As Latour (2005) comments, *"the social has never explained anything, the social has to be explained instead"* (p97). Within the interviews participants construct identifies and reveal the practical means necessary to delineate groups and keep them in existence. As Latour asserts, *"The object of a performative definition vanishes when it is no longer performed or if it stays then it means that the other actors have taken over the relay"* (P38).

I therefore feel it important to ground my interpretations through the description of the data rather than attempting to connect with wider 'social theory'. The external world is not the sea of the social in which we swim with or against the current of competing social forces and thus shaped and internally defined. Rather mediators make other mediators do things through networks of associations, the attachments are first, the actors are second. Networks are transient, fragile and uncertain and need to be established in order to make sense of context. Returning to language function and construction, within my interview data I have been mindful of McCormick's (2004; 225, 226) following suggestions in what to include when examining the data:

Table 3.7: Approach to data

What is said should include:

Words that assume common understandings or uncontested 'knowledge', or signal a request for understanding (e.g. you know)

Words that make space for thought (e.g. uhm)

Specialised vocabularies (the way particular groups or communities use ordinary words in special ways or use variants of common words that are specific to their community)

Words participants use to talk about their self-image and about relationships

How it is said should include:

Active/passive voice

Speech functions (questions, commands, statements, exclamations)

Where the personal pronouns 'we', 'I' and 'you' are used by the participant, particularly in relation to him/herself (How does she see and present herself?)

Occurrence of internal dialogue (I said, then I said) and internal or external dialogue (I said, then you said, then I said) and metaphors and other words of imagery

Within context of situation:

What can I learn from the participant's response to my open questions and to my wind-up questions?

What can I learn about our interactions from the appearance of the text?

What can I learn about our interaction from what is not said in the text?

Context of culture:

What cultural fictions does each person draw on to construct her or his view of what counts as being a person?

How have these ways of talking, thinking and being positioned each individual? Where does she or he conform to them? Where does she/he resist or challenge them? Where does she/he recreate them?

Examining the context of culture the researcher can explore the 'natural' taken-for-granted positions available to an individual to understand themselves.

Spector-Mersel (2011) identifies six mechanisms of selection through which biographical facts are filtered through in order to reach the desired end-point. They are inclusion, sharpening, omission, silencing, flattening and appropriate meaning attribution. The analysis requires the identification of these mechanisms in the positioning of teller and listener. Inclusion relates to which representing facts and events are articulated by the teller; they are subsequently given prominence through the process of sharpening. This relates to the extent of elaboration and emphasis given to a particular part of a story. The teller will generate a coda for the narrative which provides the 'appropriate' meaning attribution to which the teller wishes to embed the significance of the events that have unfolded. Omission and silencing are opposite mechanisms referring to elements that are not reported (omitted) or potentially in conflict with the desired end-point and therefore silenced. Spector-Mersel (2011) highlights that silencing is a more powerful tool of these last two since it acts as a gatekeeper of the claimed identity, preventing 'harmful' facts from entering the story. The last mechanism, flattening, relates to the summarising of events and this differs from omission and silencing only in intensity.

This analytical process is interested in both ontological narrative(s), an investigation into the nature of the phenomena, the social 'reality' under investigation, and epistemological narrative(s), which might represent knowledge of the social 'reality' under investigation (Stalker 2009). In this sense epistemological narratives are the researchers' construct based on their knowledge of the social world, whereas ontological narratives generate our social 'reality'. Ontological narratives mediate between individual events and experiences and the wider cultural context, as Stalker (2009) comments: "*we cannot know the subject, or even*

his or her experiences but we can come to know the narrative they tell” (p223). It is also “through epistemological narratives that we as researchers can start to articulate the temporal, spatial, social, cultural, political and economic connections between individuals telling of their experiences and the various social structures that are incorporated in everyday life” (p224).

In terms of data interpretation, the supervisory team viewed the transcript material and subsequent discussion and critical reflection as to both interpretation and meaning took place throughout the project (DeFina, 2009). I critically justified the narrative positioning I identified from the transcripts to the research team with the transcripts examined from two levels of positioning (Bamberg, 1997), one in relation to the context of what the story was designed to be about, the other with respect to the coordination of the interaction between speaker and audience. I can then situate the ideological positions (or master narratives) within which participants position their sense of self. Rather than a formalized coding process, this analysis examines how participants position and construct the characters within the reported events, how the participant positions himself or herself to the audience (the researcher) and to themselves. This becomes the construction of their identity to the listener. Therefore, issues such as how language is employed to make claims that the participant holds to be true and relevant above and beyond the local conversational situation is an important area of analysis (Bamberg, 2006).

3.5 Ethics

When seeking and obtaining ethical approval for this study there were a number of issues generated. The Ethics committee appeared to focus on the methodological issues of a

narrative approach rather than direct issues related to ethical practice. There were concerns regarding sampling and a focus on the generalisability of the research project. There was a concern regarding inadequate involvement of members of the psycho-oncology team and, in particular, they wished that a member of the team to be on the supervisory panel for my PhD. This discussion was subsequently not a requirement in the ethical review letter but raises ethical concerns regarding participants that could be critical about the service provision. There would seem to be a requirement for distance between participants and service providers in order to gain open, uncensored opinions regarding participant experience. A number of committee members were also concerned about how I was going to measure cognitive impairment (for example using validated measures like the MMSE) to establish a 'valid' sample of participants with dementia.

The difficulties of achieving ethical approval for research projects working with vulnerable service users is well documented (Hammersley 2009; Boden et al 2009, Juritzen et al 2011). How consent is obtained and competence assessed and determined can often be challenging to qualitative research methodologies that remain exploratory in nature. Ethics committees can be seen to favour a positivist, quantitative interpretation of science (Haggerty 2004; Halse & Honey 2007; Boser; 2007) and this standardised procedure relating to design and methodology regulates how research ethics can and should be addressed: this often limits the open, flexible and innovative designs for qualitative inquiry (Juritzen et al 2011). For example, a narrative approach tends to be unstructured and therefore I initially wished to present an open-ended question to start the interviews and then let the dialogue be taken where the participants decided. However, I created an interview guide (appendix 3) since on

previous attendance at ethics committees for other projects the committee members wished to know exactly which areas I was going to focus on. As Juritzen et al (2011) comment:

“with a basis in this concept of science, certain quite specific expectations are established with regards to design, methodology and implementation of the project with concomitant consequences for how issues pertaining to research ethics can and should be addressed ... In addition requirements tend to include the use of standardized procedures for obtaining consent and prior approval of questions in interview guides and requirements for detailed regulation of observational studies undertaken ... such monitoring practices are at odds with the (most often) open and flexible designs for qualitative research.” (pp645-6)

This methodological flexibility can be challenging for an ethics committee’s risk assessment priorities since quantifying risk comes down to ‘trusting’ the ethical integrity of the researcher. The focus moves away from procedural ethics to process ethics and what Guillemin & Gillam (2004) refer to as “ethically important moments” (p265). These are not necessarily clear ethical dilemmas but the subtle interactional exchanges and disclosures that challenge or sometimes demand an ethical (re)-positioning. This aspect of micro-ethics (Komesaroff 1995) attempts to address everyday ethical issues but is clearly not within the ethical framing of an ethics committee. Guillemin and Gillam (2004) assert that reflexivity is more than just a process of validity for qualitative research and that ethical practice can be examined and interpreted through a reflexive approach. This requires the researcher to live with ethical uncertainty and work through their ethical positioning and reminds us of the limits rather than the failure of rule-and-principle-based reasoning.

The emotional distress of some of the participants was clear within the interviews, and this generates ethical issues surrounding participant wellbeing. I was conscious of the impact that

the narrative(s) had for both myself and the teller but I was also conscious of the desire for the participants to tell their story. For example, when I contacted Alice to arrange an interview she was distressed and told me that her husband had died one week before. I was clearly not going to pursue this interview so close to her bereavement but she wanted to be interviewed and talk through the circumstances of her husband's death. As Frank (2010) comments, "The capacity of stories is to allow us humans to be" (p44). There was a clear sense that at interview, although it was distressing, Alice felt her story had been silenced and this dialogue provided the avenue for her to be heard. This was resonant with a number of other participants and reminded me how stories help people, individually and collectively, to remember who they are; how they do the work of meaning. This process is full of passion, emotion and desire, all elements that animate stories and part of performing memory (Reissman 2012, Frank 2010). One can frame this in terms of a research ethics discourse of risk management or engage with the pain and moral struggles that define us within our narrative(s) and shape the cultural positioning that we engage with. Gysels et al (2008) highlight the therapeutic nature of interviews (in a palliative care context) and suggest that it can create opportunities to empower participants. I am unsure exactly what "empowerment" means in this context but co-creating an alternative narrative frame, which narrates vulnerable lives open to devaluation. is an ethical imperative. Opening up silences and disrupting dominant narrative discourses is ethically required and the interpretative openness of narrative approaches generates dialogue, as Frank (2010) suggests: "stories have a capacity to act in ways their tellers did not anticipate".

3.6 Validity & credibility within narrative approaches: ethics and representation

There is a wider issue with narrative ethics that is important to articulate. This centres on narrative privilege, whose narrative is excluded or silenced. As Adams (2008) asserts, who has *“the ability to tell or listen to a story? What role does a medium play in the creation and presentation of a life? And how might ethical demands influence or silence the telling of a tale?”* (p180). The cultural recognition of certain narratives dictates the stories told and I, as a privileged academic, need to acknowledge the construction of the narratives of my participants and how I write and position this in order to publish these narratives. I maintain textual control over these narratives and that is why I am particularly concerned with presenting and analysing the co-construction of the data. Mauthner and Doucet (2003) remind us of the importance of explicitly articulating the precise ontological and epistemological assumptions that inform analysis and data interpretation. They also suggest a more critical approach towards our accounts and those of our participants and the conditions and constraints under which they are constructed. I agree with their emphasis that we need to *“stress the situated, partial, developmental and modest nature of these accounts as well as their historicity”* (p424). One of the challenges of dissemination, particularly publication, is to maintain the integrity of participant accounts. Resisting the de-contextualising of narratives to generic thematic outcomes in order to meet peer reviewer expectations can be a challenge and an issue I have written about (Witham 2014). Narrative approaches to analysis are not about decontextualised fragments illustrating a coding manual. I am not defining coding dimensions that are isolated and independent from each other but rather focusing on analytic structures of relationships among textual features that ground theoretical interpretation. The problem is trying to find communality within cases

without sacrificing context. The issues of validity within narrative approaches is an important area, with Mishler (1990) reformulating validation as the social construction of knowledge. He asserts that: *“validation has come to be recognised as problematic in a deep theoretical sense, rather than as a technical problem to be solved by more rigorous rules and procedures”* (P 417). Mishler (1990) has argued that all validation is construct validation and that this should involve social values and social consequences of findings rather than a technical exercise grounded by an abstract logic of methodological rules. Validation should therefore relate to the evaluation of trustworthiness (Sandelowski; 1993) of reported observations, interpretations and generalisations. Validation (rather than validity) is the key functional criteria, embedded in the general flow of scientific research work and essential to the praxis of whether findings can be relied upon for future work. Mishler (1990) wishes us to be aware of the social practice of research and notes *“All scientific reports are partisan forays into contested terrain. Nevertheless the ‘truth’ of normal science are embedded in complex networks of concepts, linguistic and technical practices and an established framework of norms and values”* (p420). The production of a research paper is a crafted fiction with methodological rules and process, a “practical accomplishment” (Garfinkel 1967) requiring refinement and pragmatic modifications based on both practical and reviewer demands. It requires a summary and an active decision-making process that excludes or includes some original features. When I have published previous work using a narrative approach (Witham et al 2014) the review comments prior to publication challenged my interpretative framework and specified data that they felt irrelevant or unnecessary material to include. They wished for a more coded thematic formatting, and I am in agreement with Mishler (1990) that:

“interpretive results view the transformations achieved by the standard model as deeply flawed distortions is that they exclude precisely those features of the phenomenon that are their essential, defining characteristics ... representing them in themes excludes both their structural and sequential features, which are specially what makes them ‘narrative’ rather than some other type of text.” (245)

By decontextualising narrative the essence of an interaction and dialogue is lost and the nuanced negotiations and positioning that characterise such encounters is sacrificed by a reductionist approach to published research presentation. According to Sandelowski and Barroso (2002) qualitative research should be judged according to aesthetic and rhetorical considerations since it is the report itself that is appraised rather than the study. The report is *“a dynamic vehicle that mediates between researcher/writer and reviewer/reader, rather than a factual account of events after the fact”* (p3). It serves a rhetorical function rather than simply a description of research performance. Validating knowledge claims is not a mechanical process but, instead, is an argumentative practice (Polkinghorne 2007: 476). My view of validation resonated with Mishler (1990) in that the questions asked should be: what are the warrants for my claims? Could other investigators make a reasonable judgement of their adequacy? Would they be able to determine how my findings and interpretation(s) were “produced” and on that basis decide whether they were trustworthy enough to be relied upon for their work? In a similar vein to Rolfe (2006) and Sandelowski (1993) one of the primary roles of the researcher is to demonstrate, via the visibility of the work, the data in the form of texts and how it was analysed. In this sense, transparency is an integral part of trustworthiness and validation. Is there a ‘decision trail’ for the reader to follow and verify the research process (Sandelowski; 1986). My methods and procedures do not in themselves

validate my finding; rather validation is a social process constructed within academic communities who may take up my narrative(s) produced within my theoretical frame and see this as trustworthy. Are my arguments persuasive enough on the basis of the evidence presented? As Polkinghorne (1988) comments:

"The conclusions of narrative research remain open-ended. New information or argument may convince scholars that another conclusion is more likely. Narrative research uses the ideal of a scholarly consensus as the test of verisimilitude." (176)

I find problematic the attempts to generate criteria for validity within interpretative approaches to research (for example, Lincoln and Guba's; 1985 criteria of credibility, dependability, transferability and confirmability). Reliability tests such as member checking (returning to the participants following data analysis, Lincoln and Guba 1985: 314, Hammersley and Atkinson 1995: 227-30) or peer checking (using a panel of experts or an experienced colleague to re-analyse some of the data) do not in themselves guarantee a more authentic avenue to the 'truth'. This rather denies the co-construction of data implicit within narrative approaches and the immanent contextual nature of data generation. Why do we wish to privilege participants' interpretation of data co-construction if our underlining epistemological foundation purports to reject a positivist position of a reality 'out there' that needs to be uncovered rather than interpreted within a cultural mediated frame? A participant has not got a unique, essential insight into the phenomenon of interest but rather stories these experiences within the cultural frame in which we interpret our lives. The performative work and positioning that occur in dialogue with the researcher are the basis for examining the meaning(s) and ways participants have dealt or navigated through the challenges of life. In similar vein, why would peer review of the findings express a greater

degree of validity or credibility? Cho and Trent (2006) define this as transactional validity, the attempt by an interactive process between researcher and researched to achieve a relatively higher level of accuracy and consensus by revisiting facts, feelings and values or beliefs collected and interpreted. They contrast this with transformational validity, research that has a progressive, emancipatory process leading toward social change. Transactional validity, which attempts to provide a quality criterion by using techniques or methods, is again challenged by Cho and Trent (2006) since validity is not an automatic given to knowledge claims by just deploying such techniques. Again triangulation (verifying facts through multiple data sources) presupposes that there exist unchanging phenomena so that triangulation can logically be a check. My research approach sits more comfortably with transformational validity in that it presupposes that meanings are multiple and socially constructed. There is also a sense where a process view of validity can be argued In which these issues are discussed (for example using a diary) as Cho and Trent (2006) comment: “validity becomes ever present and recursive as opposed to either a ‘step’ in a linear sequence or an over-reliance on subjectivity” (p 327). For validity to be meaningful in this sense it needs to relate to the extent to which data are descriptively presented and to the researcher’s competence in making sense of the daily life of his or her participants. Storied evidence is generated not to determine whether the events described actually happened as described but rather by the meaning(s) attached by the teller.

Reflexivity has also been used as a marker of validity within qualitative approaches in research (Altheide and Johnson; 1994, Cutcliffe; 2003, Buckner; 2005). Pillow (2003) suggests that:

“reflexivity is often understood as involving an ongoing self-awareness during the research process which aids in making visible the practice and construction of knowledge within research in order to produce more accurate analyses of our research.” (p178)

Reflexivity can also problematise the researcher/participant construct and suggest a more emancipatory understanding of doing research “with” instead of “on” participants. With the challenges and dubious desirability or possibility of defining any coherent, applicable criteria for validity within interpretative research, reflexivity becomes an important element in self-awareness and articulation of the challenges presented for the researcher. The trustworthiness of the research is legitimated by the researcher’s questioning of the research process. Bishop & Shepard (2011) highlight the partial and constructionist nature of any reflexive account generated by the researcher. Hindsight and insight provide only an illusion of objectivity and ‘truth’, with the researcher often unaware of how personal narrative shapes the construction and interpretation of data (Mauthner & Doucet 2003). We need to be hesitant in asserting that reflexivity can be a way to delve deeper into “social” processes not open or aware to our research participants. It is by such a route that we privilege our interpretation and almost present participants as “puppets” caught up in multiple discourses that only an academic researcher can decipher, articulate and (re)present. Such “objective” accounts are problematic. as Davies & Harre (1990) comment;

“We also discursively produce ourselves as separate from the social world and are thus not aware of the way in which the taking up of one discursive practice or another (not originating in ourselves) shapes the knowing or telling we can do Thus we experience these selves as if they were entirely our own production.” (p59)

Patai (1994) reminds us that we cannot escape our position(s) or their consequences by talking about them but rather we need to examine whether reflexivity generates more 'meaningful' research. I am in agreement with Pillow (2003) when she asserts that the practice of reflexivity is central to both revealing and leaving "what is unfamiliar, unfamiliar" (p177). I suggest not that the self is "knowable", fixed and therefore open to clear definition but rather the constructed self is constantly positioned differently dependent on context. This leads to reflexivity being operationalised in particular ways rather than being seen as a recognition of self. Butler (2005) further articulates this when she reminds us that

"I cannot be present to a temporality that precedes my own capacity for self-reflection ... it constitutes the way in which my story arrives belatedly, missing some of the constitutive beginnings and the preconditions of the life it seeks to narrate. This means that my narrative begins when things have already taken place to make me and my story possible in language ... My account of myself is partial, haunted by that for which I can devise no definitive story. I cannot explain exactly why I have emerged in this way and my efforts at narrative reconstruction are always undergoing revision." (pp39-40)

Therefore reflexivity, for me, is not a methodological device for validity, a recognition of self in the research process or a tool to represent participants better but rather a technique that allows us to be accountable to people's struggles (and our own) for self-representation and self-determination (Visweswaran; 1994). How we operationalise reflexivity is challenging and I have gained insights from ethnomethodological approaches to reflexivity. I am in agreement with the work of Macbeth (2001), who feels ethnomethodological approaches may offer a more productive insight into reflexivity in that not only does it remove binaries and representational language games but the work of reflexivity is made redundant and

incorporated into the practical achievements of diverse settings, occasions and practices. A “constitutive reflexivity thus has no use for non-reflexive worlds and makes no sense as a demarcation exercise” (Macbeth 2001: 55). Reflexivity is more a descriptor of ‘accounts’ and predicates actors to make their actions accountable through and in these actions themselves (Czyzewski 1994). So rather than reflexivity being generated, for example, by the researcher in hindsight, it actually becomes a part of the interview dialogue itself, generated at time of interview. As Coulon (1995) suggests:

“in the course of our ordinary activities, we do not pay attention to the fact that while we are talking, we are building up, at the same time that our words are uttered, the meaning, the order and the rationality of what we are doing. The description of the social world become, as soon as they have been uttered, constitutive parts of what they have described.”
(p23)

3.7 Positioning Theory

I have incorporated aspects of Positioning Theory (Harre & van Langenhove; 1999) within my analysis of the data since this can provide a framework in which performativity is enacted with the positioning of the self in personal narratives signifying the performance of identity. There is an assumption that *“rules are explicit formulations of the normative order which is immanent in concrete human productions, such as actual conversations between particular people on particular occasions”* (Davies & Harre 1990: 44). Positioning Theory is therefore grounded in everyday conversation and involves teller and listener negotiating the construction(s) (or attempted construction(s)) of action mediated towards social practice. It addresses features related to the local context and is focused on highlighting the explicit and implicit patterns of reasoning that are generated in the ways that people act towards

others. Identities are fluid, shaped, (re)-constructed dependent on the available positions open to participants within their discursive practices, and challenged, solidified or open to change dependent on these interactions. These positions are implicitly generated through storied lives and as Davies & Harre (1990) comment, “in this way poststructuralism shades into narratology” (p46). In a similar delineation to Sacks’s (1967) Membership Category Analysis, Positioning Theory asserts the categorical nature of learning that explicitly exclude or include certain people, for example father/daughter and that these both position the self and affect story lines initiated. This also implies a recognition and association of specific categories for oneself and the moral imperatives associated with this category membership. Positioning is not a necessarily intentional, the production of self is ongoing and as Butler (2005) comments *“my account of myself is partial, haunted by that for which I can devise no definitive story. I cannot explain exactly why I have emerged in this way and my efforts at narrative reconstruction are always undergoing revision”* (p40). The autobiographical derived aspects of conversation become an entry point to conceptions of self and for other participants their relation to these stories and the type of stories told ground how they are positioned. The metaphors and images taken up in conversation call the speaker and listener to certain ways of being which are culturally mediated and invoke particular responses that participants may be unaware. This is not necessarily non-contradictory in relation to a participant’s autobiography and reflects the fragmented nature of all narrative construction. The cultural context in which narratives derive and are (re)-constructed is an important element within dialogue as Davies & Harre (1990) comment: *“One speaker can position others by adopting a story line which incorporates a particular interpretation of cultural stereotypes to which they are ‘invited’ to conform, indeed are required to conform if they are to continue to converse with the first speaker in such a way as to contribute to that*

person's story line" (p50). The co-creation of the narrative requires the taking up of these cultural stereotypes and also an awareness of the underpinning narrative genres invoked. Mattingley (2010) refers to this as "narrative mind reading" and if within, for example, clinical interchanges with health professionals there is misreading this can lead to "atrocious stories" (Stimson & Webb 1975) often leading to a breakdown in the relationship with health professionals.

Within Positioning Theory there are unfolding narratives in which we can refute the subject position(s) that a speaker asks us to take up within available discourse. Particular attention is paid to the normative opportunities and constraints for action within any (en)actment and what practices are 'allowed' within any unfolding given story line, what is sayable or doable under these conditions of dialogue. A narrative analysis, therefore, reveals the normative constraints within story line development as expressed "*in the alternative language of locally valid patterns of rights and duties*" (Harre et al 2009; p.6). Positioning Theory is primarily the study of meanings and how they become embedded in practices. It focuses on three interdependent aspects of interpersonal encounters. The first involving the distribution of rights and duties among people in changing patterns as they perform certain types of action. The conceptual interpretation of "rights" and "duties" is articulated as our moral (normative) presuppositions underpinning and framing the positions within immanent conversational action. Secondly, these patterns are produced by higher-order acts of positioning through which these rights and duties to ascribe or resist positioning are distributed. These actions are important elements of story lines and may support simultaneous, multiple story line development. Finally, those meanings are derived from social acts embedded within the interpreting local community to which it is ascribed, and it

is this community which determines this story line although any action might signify multiple meanings (Harre et al 2009). Positioning occurs in dialogue and as such is a discursive process. Aspects of Positioning Theory have been utilised within narrative approaches, with Taylor (2006) and Taylor & Littleton (2006) presenting a narrative-discursive approach in which the production of identity work can expose commonalities in biographical talk and situate resistance and (re)negotiation in this ongoing construction of personal identity. Positioning Theory is also concerned with what Shuman (2012) describes as a question of “entitlement” (p126). Who can say what statement, what narrative is acceptable and how this is negotiated? She characterises narrative interactions into tellability/reportability, ownership/entitlement, footing the use of genres, performance styles and reported speech. Other elements of importance include intertextuality and dialogic narration, social or political membership categories and finally conclusions. The term “footing” derives from Goffman (1981) who took this concept as implying a change in the alignment we take up to ourselves and others in the production and reception of an utterance. Footing for Goffman (1981) related to the projected self, which could be presented in behaviour less than a grammatical sentence so sentence grammar may not detect it (although Goffman thought minimally this would include a phonemic clause). Footing should also be conceived as a continuum from obvious changes in position to subtle manoeuvring and it often involves code switching. It is a change in our frame for events and this is a persistent feature of natural talk. Narrative becomes a mechanism to establish a footing or alignment with the listener and with different categories of people. Positioning, as Shuman (2012; 135) comments, becomes “interactive, intertextual and dialogic”, with negotiations of tellability, ownership and positioning situated “at the intersection of narratives as texts and narratives as interactions”.

3.8 Transcription process

I have transcribed my own data from the interviews and I have utilised Chafe's (1994) intonation units to characterise the segmental nature oral speech within the transcripts. Chafe defines intonation units as potentially involving a number of elements including changes in frequency (pitch), changes in intensity (loudness), changes in duration (perceived as the shortening or lengthening of syllables or words), alternations of vocalisation with silence (perceived as pausing), changes in voice quality and occasionally changes of turn. Chafe (1994) further asserts that the identification of a coherent intonation unit is established by the convergence of "(a) the pauses preceding and following it, (b) the pattern of acceleration-deceleration, (c) the overall decline in pitch level, (d) the falling pitch contour at the end and (e) the creaky voice at the end" (p61). Intonation units can be fragmentary and never reach their terminal contours but can also be subcategorised into those that convey substantive ideas of events, states or referents and those that have regulatory functions in terms of regulating interaction and information flow. Regulatory units can be textual, for example "and then, well", interactional, for example "mhm, you know", cognitive, for example "let me see, oh" and validational, for example "maybe, I think".

In terms of the size of the intonation units, the mean length of regulatory units is 1.36 words and thus the regulation of discourse is brief whether textual, interactional, cognitive or validationally. The mean length of substantive intonation units in the measured sample by Chafe (1994) is 4.84 words and hence "a focus of consciousness is typically expressed with four words of English" (p65). Speakers aim to articulate a focus of consciousness in the format of a clause and this is often asserted in the idea of an event or state. An event relates

to something that happens, either as something someone does (action) or something that happens to someone or something (a change of state). A state, rather than happening, simply exists for a period. So as Chafe (1994) comments:

“if we think of a typical substantive intonation unit as having the form of a clause and if we think of a clause as verbalising the idea of an event or state, we can conclude that each such idea is active or occupies a focus of consciousness, for only a brief time, each being replaced by another idea at roughly one- to two-second intervals. Event and state ideas, in other words, are highly transient in active consciousness. They are constantly being replaced by other event and state ideas” (p66). This attention to active consciousness has led me to attempt to represent my data through intonation units.

3.9 Summary of chapter

This chapter has examined the performative narrative approach (Reissman 2003) I have taken and the underlying social constructivist stance integral to this interpretative framework. I have explored my understanding of narrative and have articulated the methods I have used to address my research aims. These include exploring the experience of carers who have supported a relative with cancer and dementia and to use a performative narrative approach to examine the positioning of both teller and listener and the implications this suggests for carers. They also include examining what this positioning means in terms of healthcare professional response and the implications this may have in clinical practice. I have further highlighted how I am going to examine the data (McCormack 2004) and the importance of positioning from both the teller and listener within an interview encounter. I have explored issues of validity and credibility within narrative approaches and the potential challenges or differences to other qualitative approaches to

quality indicators. I have examined issues surrounding the transcription process and what aspects of conversation I am interested in examining. The following chapter will explore the findings and each interview encounter separately and examine the narrative positioning that thread throughout the interview(s). This is in keeping with a narrative approach (Reissman 2008) in respecting a holistic exploration of the context of the interviews rather than attempting to code and fragment these data. Areas of commonality between participants will be further explored in the discussion chapter.

Chapter 4

Findings

4.1 Introduction

This chapter will examine the sample characteristics generated from the participants. These findings are presented in a case study format, examining each participant's narrative in order to explore, in depth, how they position themselves within an interview context. This generates a more holistic view of these data than codifying and categorising the narrative, and the reader can more readily connect narrative commonalities throughout the participant stories. It is important for validation to show how the co-construction of data is generated, therefore the data examples are unpacked and the teller/listener interactions have been analysed and contextualised within the interaction of the interview. I have also described my transcription conventions.

4.2 Sample

Recruited caregivers had different familial relationships and the sample included daughters, partners, brothers-in-law and siblings. The issues and narratives generated did not appear to depend significantly on the different familial relationship identified. Interestingly, throughout the interviews support from the psycho-oncology team was not a significant feature of the narratives explored by the participants. The participants were between 50 and 70 years of age and the care recipients' cancers were diverse, with two living with more than one cancer. These included bladder, prostate, lung, oesophageal, sarcoma and penile cancers. Two participants, Alice and Betty, were widowed. Through participant reporting there was a range of dementia stages of the participants' relatives, from those having

limited mental capacity and advanced dementia (the relatives of Susan, Betty, Lynne and Alan) to those who had insight into their cognitive impairment (the relatives of Jane, Alice and Lauren). Two Relatives had vascular dementia, one a mixed dementia and the others had Alzheimer's disease. The participants were the primary caregivers for their relative. Interviews times were recorded lasted up to 60 minutes. There are some limitations to my sample, in particular recruitment via the psycho-oncology team meant that most of these participants were identified as requiring extra support and this may be indicative of an atypical treatment journey for the participant's relative. We also know that a large percentage of people are living with an undiagnosed dementia and therefore this study would not capture that experience for carers. I also did not account for all familial relationships (particularly primary male carers) and therefore we may not have captured narratives positioned differently to the participants in this study. The sample size is small but this is an exploratory study and the thick description generated provided rich data. The post ethics amendment meant that two participants were recruited via snowball sampling and the gatekeepers (academic colleagues) initially approached potential participants. If they were interested and wanted further details information sheets were sent. If they wished to participate informed consent was obtained prior to interview. The 2 participants (Lauren and Betty) did not generate significantly different narratives throughout the interview than those recruited from the psycho-oncology team and the participant characteristics were similar.

Table 4.8: Characteristics of sample

Participants	Age range of participants	Relationship of carer to person with dementia	Living situation	Cancer of relative
Lauren	50-60	Daughter	Living with mother	Bladder & prostate
Lynne	50-60	Sister	Living separately	Lung cancer
Alan (Lynne's husband)	50-60	Brother-in-law		
Betty	70-80	Partner	Widowed (alone)	Oesophageal & prostate
Alice	70-80	Wife	Widowed (alone)	Penile
Jane	50-60	Daughter	Living separately	Oesophageal
Susan	70-80	Wife	Living together	Sarcoma

4.3 Transcription conventions

I have followed Norrick (2010) in my transcription conventions including each line of transcription containing a single intonation unit (prosodic phrase). This form of representation can better characterise spoken language and is based on the work of Chafe (1994).

She's out. Period shows falling tone in the preceding element

Oh yeah?	Question mark shows rising tone in the preceding element
Well, okay	Comma indicates a continuing intonation, drawling out the preceding element
<i>Damn</i>	Italics show heavy stress
Bu-but	A single dash indicates a cutoff with a glottal stop.
Says “Oh”	Double quotes mark speech set off by a shift in the speaker’s voice
[and so-]	Square brackets on successive lines mark[?]
[Why] her?	Beginning and end of overlapping talk
And=	Equals signs on successive lines shows latching
=then	between turns
(2.0)	Numbers in parentheses indicate timed pauses.
{sigh}	Curly braces enclose editorial comments and untranscribable elements

4.4 Data selection

The data extracts identified have been selected to represent some of the recurring narrative themes that were generated from these data. Reissman (2012) reminds us of the seductive nature of story telling and the prerequisite for a story to capture and maintain interest. As a researcher the importance in data selection is to make transparent the positioning within the dialogue and expose how stories are used in conversation. The extracts are used to highlight the developing narrative genres and positioning required for the participant to “convince” the audience of the strength of their argument. This may be more mundane descriptions of events or stories that build up to dramatic climax to illustrate and highlight the interpretation of the teller. With either type of extract the inclusion of the data are designed to demonstrate the participants positioning and to expose some of the underlying

repetitive motifs within story-telling from the cultural frame that they are derived from. This process allows for comparison between cases and context of the data generated.

4.5 Jane's story:

"and the cancer to be honest was the least of me worries"

Jane was interviewed in a rural setting at her work site. She was supporting both her parents who were living with dementia, with her father also diagnosed with oesophageal cancer. She had a partner and a brother and was in her 50s. The narrative(s) of the interview were intertwined with the nuanced complexities of care and the subsequent accounting required for her positioning as a competent carer. Jane through nonlinear narratives at times loses track of links she has posited between events and this often indicates the fractured, unfinalised nature of stories and their capacity to act in ways their teller did not anticipate (Frank 2010). She was fast paced in her speech and direct. On reflection this was reminiscent of the experience of Mattingley (2010) in her interviewing people in a crisis of life: *"Many of them don't need much in the way of pleasantries. Time has changed, it's speed, it has become concentrated, portentous. It may be too fast or too slow but it is never luxurious"* (p2). This was particularly evident in Jane's interview as she 'flattened' stories with non-lexical utterances such as 'bah, bah, bah' to quickly focus on the essential nature and significance she attaches to a story.

Jane's narrative(s) shifted between concern with troubles related to her father and then in relation to her mother as competing moral claims to her positioning as a carer. The point of crisis requiring formal services came after her mother was ill with a urinary tract infection

and the stress reaction this induced in her father. Jane described the subsequent dialogue intimating a risk of suicide:

1 **Jane:** Err
2 Dad's temperament
3 went
4 around us
5 and this time
6 when she was really ill
7 the doctor came out
8 and I ended up bursting into tears
9 with my brother
10 saying to the doctor
11 we can't cope with this
12 we can't cope
13 she said
14 right
15 just do another night
16 and we'll try
17 and get her into respite
18 try
19 and stick another night
20 so we said yeah
21 and the following morning
22 me Dad said to me brother
23 we've been talking last night
24 me
25 and your mum
26 err
27 you'd be better off without us
28 what do you mean?
29 Well you
30 and Jane
31 are better off if me
32 and your mum were dead
33 we were talking about it last night
34 he said
35 what do you mean?
36 don't be daft
37 don't be daft
38 he said
39 yeah
40 we've been talking
41 about what tablets we could have

42 So I rang the doctors
43 then told the doctors
44 and then
45 right
46 you need to get mental health involved
47 now

Jane sets the scene by letting the listener know the seriousness of the situation with her open emotional response to the GP and further justifies such a response by citing her brother's own inability to manage the crisis. The 'blow-by-blow' form of telling unlike a summary pulls the listener into the specific moment (Riessman 1990) and creates a window into the emotional life of Jane and her brother. This moral challenge is presented to the GP who offers potential respite; however, moral adequacy is further challenged by positioning the reported speech of the dialogue between her brother and her father. The flow of actions and events is broken down into very small units by representing single speech acts. The passive statement of wishing themselves dead followed by a minimising of this desire by her brother is juxtaposed to the following utterance related to an active search of the kinds of tablets to take. This heightens the listener's concerns justifying Jane's assertion that formalised, professional care needs to be urgently introduced. A call to action has been invoked. It also maintained Jane's moral adequacy as a carer since no 'reasonable' carer could cope in such circumstances without health professional support.

Jane describes the day-to-day positioning required to account for being a carer in terms of providing, for example, a diary listing events that will take place that day, labelling for kitchen appliances and instructions for using the washing machine and tumble dryer. This was in spite of a challenging relationship with her father whom she positions as "a naughty pig", "stubborn" and having a "blaming temperament". Her mother is presented as more of

a passive figure reduced to such by vascular dementia as opposed to the mixed dementia Jane attributes to her father. This diagnostic sophistication offered by Jane positions her as someone who is aware and informed of the variants of dementia and also presents her interpretation of what the differences clinically mean. So her dad is “going slow and he’s on the tablets to slow it down” whereas her mum’s is vascular so “mum’s is going to go like that” (Jane indicates a downward spiral with her hands). This characterisation presents its own challenge for Jane as the excerpt below indicates:

- 1 **Jane:** It’s not always possible
2 and
3 err
4 so
5 obviously
6 he isn’t as bad as mum
7 mom had suddenly gone
8 from doing everything
9 to doing nothing
10 she even forgot how to cook
11 she forgot how to use the cooker
12 she can’t
13 she couldn’t
14 at the beginning
15 decide
16 what
17 she was pushing the button
18 at the side of the toilet seat
19 instead of the button to push the chain
20 **Interviewer:** oh right
21 **Jane:** her whole concept
22 everything
23 had just gone?
24 **Interviewer:** yeah
25 yeah
26 **Jane:** and we were
27 well it doesn’t matter
28 you’ve gone
29 your turn
30 it doesn’t matter
31 is
32 is

33 dad's temperament
 34 is a blaming temperament
 35 always been
 36 err
 37 somebody's fault
 38 and
 39 err
 40 of course
 41 he's got to look for someone else to blame
 42 **Interviewer:** yep
 43 **Jane:** so all the time
 44 he's saying to her
 45 you're not trying hard enough
 46 You're not trying hard enough
 47 she's not doing this
 48 or not doing that
 49 and of course
 50 he's got the dementia
 51 we can't explain to him
 52 keep telling him
 53 and telling him
 54 doesn't work
 55 because it doesn't go in
 56 when
 57 **Interviewer:** yeah
 58 **Jane:** she isn't going to change
 59 she isn't going to get better
 60 Coz
 61 then he says
 62 we're being negative
 63 so it's coping with two
 64 I think if we had one
 65 it'll be a lot [easier]
 66 **Interviewer:** [yes, sure]
 67 **Jane:** with two of them
 68 **Interviewer:** yeah

Within this dialogue Jane sets the scene, informing the audience of the drastic change of her mum's competence from 'everything to nothing', and highlights an exemplar of this with fundamental aspects of self-care; cooking and toileting (lines 9-17). The technical inability

to use the toilet was presented by 'atomizing' (Gulich & Quasthoff; 1986) the dialogue to highlight the specific inappropriate action(s) performed and then she informs the audience of what her mum should have done if we were to deem her competent (line 17). After my acknowledgement token, Jane follows in the dialogue with a reiteration and summary of her mother's level of competence and then presents a contrast between her attitude and the more negative connotations associated with her father's position. It is common for tellers to collaboratively affirm their own moral stance in opposition to a rival moral perspective (Ochs & Capps 2001), so following my continuer 'yep' Jane uses direct reported speech to highlight her father's critical attitude. She, however, then draws the listener back to positioning her father as morally adequate in the light of the capacity issues related to a dementia diagnosis. This ambiguous moral positioning was evident throughout the narrative(s), with Jane simultaneously casting her father morally culpable but also reasserting to the audience the moral mitigation necessary for someone whose understanding and comprehension is compromised. Following my acknowledgement token, Jane affirms to the audience the poor prognostic outcome related to her mum (both in the present and the future), and contrasts this with a charge of negativity posited by her father. Jane maintains moral adequacy by previously positioning her father as lacking comprehension and therefore having unrealistic expectations of his wife's prognosis. Jane presents a pessimistic picture of both parents and highlights the challenges of maintaining hope. As Mattingley (2010) asserts:

"cultivating a hopeful stance is paradoxical, it involves an ongoing conversation with embittered despair. To hope is to be reminded of what is not and what might never be." (P3)

The coda of the narrative conveys the significance of the story and Jane summaries the problem in terms of a double burden with two relatives with dementia. She intimates to the audience that managing one would be a 'reasonable' burden but then presents the difficult reality, the 'unreasonableness' of two. This is met by my acknowledgement token, I affirm the difficulty of this situation and in response Jane reaffirms the nature of the problem.

Jane returns to this summary of her troubles throughout the interview and her accounting as a carer is shaped and mediated through the lens of a double care burden complicated by differing cognitive abilities between her mother and father.

Jane presents the negotiations required with her father in order to maintain the fiction that he provides most of the care for his wife and can also manage his life in the way he used to. Elaborate positioning was required in order to support this illusion and maintain his moral integrity. For example, Jane noted that this could involve not contradicting him within an outpatient context in front of medical staff to prevent embarrassment or in trying to support her father in managing her mother's incontinence problems. Trying to get her father's consent for her mother to go into respite whilst he had radiotherapy as an inpatient was challenging to Jane and reveals the performative aspects of negotiation as this dialogue highlights;

- | | |
|-----------------------|--|
| 1 Jane: | erm, he said to me short term |
| 2 | he wouldn't take it from us |
| 3 | but he will take it from somebody |
| 4 | who he sees as cleverer |
| 5 | or |
| 6 | in authority |
| 7 | or |
| 8 | professional |
| 9 Interviewer: | yes |
| 10 | professional |
| 11 | yeah |
| 12 Jane: | so we had to get them to back us up [really] |

13 **Interviewer:** [yes]
 14 **Jane:** and them to suggest it
 15 oh, yeah
 16 **Interviewer:** that's a good idea
 17 **Jane:** so we have to do that a lot
 18 err because to him I'm just a child
 19 that's what he said to me
 20 when he threw me out the house
 21 **Interviewer:** yeah
 22 **Jane:** you're only a child
 23 I said *I'm 57*?
 24 **Interviewer:** yes {laughing}
 25 I suppose in their eyes
 26 you'll always be the daughter
 27 won't you
 28 **Jane:** I will always be his child who knows nothing
 29 according to him
 30 **Interviewer:** yeah
 31 yeah
 32 **Jane:** so errm
 33 they explained that he really needed to stay in
 34 because if they could keep him in there
 35 on the liquid paracetamol
 36 the fortisips
 37 **Interviewer:** yeah
 38 keep him eating to some degree
 39 he might not need to have the tube

In this 'trouble talk' (Jefferson 1988) Jane presents her father as someone not listening to his family and she categorises the attributes that are required in order for her dad to take seriously any care suggestions offered. After my acknowledgement token Jane attempts to position herself as a co-ordinator of care by instigating professional help and invoking that authority to negotiate with her father. This was not presented as an opportunity to discuss or question the decision to a third party but rather as a strategy to facilitate her father's compliance. Following this through reported direct speech, Jane demonstrates both this strategy and its performance with "oh, that's a good idea" and then indicates to the audience the frequency of such constructions on the basis of the membership category of

father/daughter (Sacks 1992, Baker 2004). This membership category is problematised with the adverb 'just' and then by an action contravening the usual category associations of father/daughter since it would not be usual to throw a daughter out of the house. After my continuer 'yeah' Jane further reiterates the positioning of her father and then presents a direct challenge with 'I said I'm 57'. I acknowledge this; my laughter initiated by the commonsense absurdity of the association of 'only a child' with Jane's current age. I further support the membership category of daughter/father, and this is acknowledged by Jane who then qualifies and challenges the formation of a membership categorisation device that 'children know nothing'. Paoletti (2002) asserts that caring can be considered a category-bounded activity associated with certain kinship categories and evoked in relation to the distribution of caring duties, in particular 'standardized relational pairs' such as daughter/father (Sacks 1967). Sacks (1967) comments that a standard relational pair *"constitutes a locus for a set of rights and obligations concerning the activity of giving help. Caregiving is certainly one of these activities definable as 'help' that are bound to standardized relational pairs."* (p203)

At the end of this dialogue there is an exit and boundarying off in which Jane retreats to an information segment, a sequencing of 'factual' linear events. As Jefferson (1980) has noted, central to trouble talk is the constant tension between attending to the trouble and attending to business as usual. The parties start out at an interactional distance appropriate to their routine conversation, become gradually closer, arrive at an intense intimacy as the trouble is focused upon and then returns to a more distant relationship as they re-engage with business as usual.

Maintaining an identity as a carer was challenging for Jane both in working with formalised care providers and throughout her recent employment history. Jane worked in a campsite and to enact the role of carer required employer flexibility. Within the narrative Jane presented a contrast between her previous employer and current employer and highlights the contested position of carer, its precarious, fragile and vulnerable position within the workplace. To maintain moral adequacy requires other agents to support this role, so for Jane “*can we work with these people*” is a foundational requirement for any prospective employer. Within the dialogue Jane refers to her previous manager as inexperienced and generalised the discussion to include the low social status associated with the campsite industry as grounds for an inflexible approach. Jane creates moral authority by informing the audience that she has been in a senior management position and can therefore expertly comment on the management issues she subsequently raises. Jane couples her manager’s inexperience with inadequate training in providing the appropriate empathetic response. Jane presents her difficulty with certain management styles in this dialogue:

- | | |
|------------------------|---|
| 1 Jane: | we can’t always get that |
| 2 | and we know that |
| 3 | having worked on a different site |
| 4 | with a lot more people |
| 5 | with someone who’s never managed people before |
| 6 | thrown into it managing people without any training |
| 7 | and couldn’t cope |
| 8 | and the only way she coped |
| 9 | was by being rigid |
| 10 Interviewer: | yeah |
| 11 | yeah |
| 12 Jane: | with everybody |
| 13 | We- we’ll swap amongst ourselves |
| 14 | <i>I don’t want you to swap amongst yourselves</i> |
| 15 | <i>because I’ve done a rota</i> |
| 16 Interviewer: | <i>no control</i> |
| 17 | <i>no control</i> |
| 18 Jane: | yeah |

19 yeah
20 Exactly
21 no control over anything
22 errm
23 so we had a few conversations

Jane initially creates an association with inexperience and rigidity, implying this stems from an inability to cope. She presents an empathetic response to poor management style by asserting that inappropriately trained people are positioned within a management context, they are “thrown into it”. Following my acknowledgement token Jane implies her manager is isolated and separate from the other staff and that they can adequately manage their shift patterns. Through quoting direct speech and imitating the manager phonetically Jane immediately positions a response presented which confirms rigidity rather than offering a reasoned account of the decision-making process. I support Jane’s interpretation with a summary positioning the manager phonetically as panicking and foundering and Jane confirms this assessment and takes up this interpretation requiring her intervention and discussion with the manager. This management style is presented as incongruent with her identity as a co-ordinator of care and therefore needs to be addressed.

With Jane’s interactions with formalised care, attempting to convey the complexities of care was challenging. For example, for pain and then thrush caused by radiotherapy Jane describes how her father was prescribed medication for thrush that he needed to keep in his mouth before swallowing. This simple prescribing act is juxtaposed with the complexities of clinical management since he already has liquid paracetamol to have half an hour before food which he forgot to take and then he was encouraged to drink but not for an hour after the medication for thrush. Jane describes seeing her father drink tea immediately after taking this medication and she conveys these situated problems to the

audience. Jane further presented herself as a co-ordinator of care in terms of managing various healthcare appointments for her parents and this involved sorting through their mail and (re)arranging appointments as necessary. As Jane describes in this dialogue:

- 1 **Jane:** you've got all these different people involved
2 and it just gets
3 (2.0) so much to handle sometimes
4 **Interviewer:** yeah
5 **Jane:** so I can't cope with the
6 (1.0) caring bit
7 because I'm too busy with the organisation bit
8 **Interviewer:** yeah
9 yeah
10 it feels sort [of]
11 **Jane:** [when I go]
12 I'm looking at the mail
13 reading the mail
14 sorting appointments out
15 like this comes {Jane shows appointment letter} the same day as
16 you're due
17 to go to the fracture clinic
18 so that can't happen
19 **Interviewer:** right
20 ok two appointments on the [same]
21 **Jane:** [and the day] before
22 she's got another appointment
23 so I'm going to have to go
24 early one
25 err
26 late one night
27 sleep over for one appointment
28 stay the following night for another appointment
29 because there's one after another
30 **Interviewer:** yeah?
31 **Jane:** and now they want to come as well
32 so they're {Jane's niece's} gonna to have to come
33 Tuesday afternoon
34 or Wednesday morning
35 to fit in or a different week
36 but I've started to get firmer now
37 saying
38 no that doesn't fit and
39 **Interviewer:** oh [good]
40 **Jane:** [and] they make you feel horrible

41 **Interviewer:** oh
 42 **Jane:** *why can't you bring your mum?*
 43 *why can't you bring your mum?*
 44 Well I live and work in {name of county}
 45 mum and dad are both ill
 46 I can't bring me mum that day
 47 cos me dad is at (name of cancer centre) that day
 48 **Interviewer:** right
 49 **Jane:** right ok
 50 and that's priority at the moment
 51 **Interviewer:** yeah
 52 **Jane:** and you have to be quite firm
 53 **Interviewer:** yeah
 54 yeah
 55 **Jane:** if I wasn't that type of person
 56 it would have been a lot worse

Jane presents the work required to account for caring: the co-ordination and management of an unspecified series of people within this care context. After my continuer 'yeah' Jane positions herself as an organiser of care rather than situated within direct care management, she distinguishes a difference between 'the caring bit' and organisational responsibilities and frames this difference directly within a time management context. The complexities of her parents' needs require her to position herself as a key co-ordinator of care. I respond with an acknowledgement token and begin affirming this role when Jane continues with an exemplar justifying her position: she describes the tasks required to enact this role and presents to the audience the dilemma of a clash in appointments. My acknowledgement token is followed by another example of the consequences of receiving multiple appointments in the post and Jane describes the blow-by-blow accounting of this in having to stay overnight with her parents. The relatively simple act of opening post can unravel into a complex set of requirements to perform the role of a care co-ordinator. Within this dialogue Jane further separates formal health providers from her identity as carer by describing them as 'they' and enacts her position as care co-ordinator by specifying

to the audience what days they can attend within the week. This requires the attribute of being 'firm' and challenging the contested position of carer within the context of health professional positioning. To do so is to maintain moral adequacy but comes at a cost. I respond to this with an empathetic token and Jane presents her emotional response of such positioning. She feels 'horrible' and this leads to my questioning with the non-lexical response of 'oh'. Jane quotes direct speech in response to my questioning imitating a nameless person with a repetitive accusatory question. She presents her response to this, again highlighting the complexities of her situation and then challenges the agenda set by formalised care providers by asserting to the audience that she sets the priorities of care. In order to achieve this Jane again refers to being 'firm', locating this as a personal attitude that not everybody possesses.

Maintaining moral adequacy as a carer was a key concern for Jane, and it manifested and intertwined throughout her narrative(s). For example, she attended to a story of her mother locking the door of her grandmother's room after she was given a diagnosis of dementia to prevent wandering. She presents this dilemma to the audience and proceeds to answer the following moral question which her story seems to answer: "how could you lock your mother in her room?" In answering this question Jane is attending to the issue of her grandmother's appearance as a moral person. This same thread attends to issues like trying to support her father in maintaining his status as a husband and in managing the associated risks and safety to her mother in enabling (t)his position. Jane was aware of the prognostic 'script' that was unravelling before her, her mother deteriorating, unable to engage with or maintain any self-care, and her father who had survived cancer but his dementia was slowly robbing him of the insight he retained. Maintaining their appearance and status presents a

morality tale in which Jane presents to the listener the renegotiation and re-boundarying of hope required to maintain her position as morally adequate, as the dialogue below illustrates.

- 1 **Interviewer:** kinda thing
2 doesn't it
3 you know
4 errm
5 and
6 I know sometimes
7 speaking to other people who are carers
8 sometimes cancer treatment can be delayed
9 in itself
10 because of all these issues
11 and I know that it causes worry
12 do you know what I mean?
13 I-I-I
14 -it's just an extra burden really
15 isn't it?
16 **Jane:** you do
17 it goes through your mind
18 you think
19 well if they had told him
20 they'd have to keep him in
21 for a month
22 3 and a half weeks
23 he probably wouldn't have had the treatment
24 **Interviewer:** no
25 **Jane:** then part of you thinks
26 (5.0) and this is horrible
27 (1.0) you've got to die of something
28 and that would have been quicker
29 than this that's happening to him now?
30 **Interviewer:** yeeah
31 **Jane:** because this that's happening to him now
32 is horrendous
33 **Interviewer:** yeah
34 **Jane:** and it's happening to mum
35 and you see them go
36 and slip away
37 a bit at a time
38 **Interviewer:** yeah
39 **Jane:** then you're thinking
40 well

41 would it have been better
 42 if he didn't have the treatment
 43 would it have been better not to
 44 and
 45 **Interviewer:** [yeah]
 46 **Jane:** [and] somebody coped with the pain
 47 it would be quicker for him
 48 **Interviewer:** yeah
 49 **Jane:** it wouldn't have been nice
 50 whatever way it's not going to be nice
 51 if it's not gone
 52 it's not going to be nice
 53 it's not nice
 54 **Interviewer:** yeah
 55 **Jane:** if we have to tell him
 56 we can't look after him at home
 57 and they both have to go in a [home]
 58 **Interviewer:** [yes]
 59 **Jane:** and I suppose in one way
 60 for you
 61 as a person
 62 it's
 63 it's a cop out
 64 **Interviewer:** yeah
 65 because you're looking thinking
 66 in your head you can see things
 67 **Jane:** yeah
 68 **Interviewer:** on the horizon
 69 **Jane:** yeah
 70 **Interviewer:** thinking
 71 Ohh
 72 how's that going
 73 to work out
 74 **Jane:** yeah
 75 it's like when you
 76 me mum's not well
 77 and asleep
 78 and you're sitting there
 79 holding her hand thinking
 80 mum just go now
 81 in your sleep
 82 **Interviewer:** yeah. [softly]
 83 **Jane:** because she's not happy
 84 he's not happy
 85 **Interviewer:** yeah
 86 **Jane:** than just surviving
 87 **Interviewer:** yeah

88 **Jane:** there isn't any
 89 **Interviewer:** are you worried about quality of life?
 90 **Jane:** yeah
 91 that's about
 92 that's exactly what I was going to say
 93 they haven't any quality of life
 94 really
 95 **Interviewer:** right
 96 **Jane:** and I said to my brother the other week
 97 I suppose we have got to get
 98 we have to get it into concept
 99 get it in perspective
 100 and just say right
 101 they're at home
 102 where they want to be
 103 they're warm
 104 and they're fed
 105 **Interviewer:** mm

I approach the issue of burden to Jane and suggest an issue of delay in diagnosis that I further validate by positioning other carers as also experiencing this. I then offer an empathetic response of naming Jane's feelings and ask for a validation of this with "do you know what I mean". I make claims about her emotions and this 'allows' Jane to put forth in more detail her feelings about the situation (Pudlinski 2005). Jane takes up this sympathy token to create the space and permission to present a different but potentially better scenario, a 'hypothetical' narrative (Riessman 1990) – one that involves no radiotherapy but contests the moral adequacy of Jane. This threat to her identity is acknowledged and pre-empted by a 5-second gap followed by "and this is horrible". Jane uses this approach device to announce the trouble and to acknowledge to the audience the morally contested nature of this alternative story. This may become a transgressive story (Norrick; 2008), the teller risks rejection by the listener refusing to hear the offensive story and negatively judging the teller for the attitude reported. Alternatively, the teller may gain the listener's admiration for the experience reported. Jane contrasts the prognostic outcomes of dementia and

cancer to the audience and asks the question: which is quicker? After my acknowledgement token, Jane again presents the current situation as grounds to morally justify this position and expands it to include her mother as well. Jane switches back to her father and asks the listener to address the dilemma about treatment: should he have cancer treatment or not? It is a hypothetical dilemma but demands an answer to maintain moral adequacy. Jane contextualises this statement by positioning any outcome as problematic: maintaining hope requires ongoing identity work. Jane presents an unbearable future by asking the listener to imagine her parents separated and in a care home. She then positions the dialogue to address her own moral adequacy by referring to it as a “cop out”. Jane’s “cop out” focuses on moral resilience: has she the courage to stay the course within a hopeless future? I acknowledge and affirm this, the reality of future trouble is clear. This process represents “fore-shadowing” (Ochs & Capps; 2001): the narrator(s) know what will follow and cast characters and events in terms of this future trajectory. Jane reaffirms this future trajectory with acknowledgement tokens and presents her wish for her mother to die in her sleep within this framework of future trouble. She is not happy and Jane takes up my suggestion about this relating to issues of quality of life, affirming this interpretation. Jane then presents the coda of this narrative: that this hypothetical positioning cannot alter the future; her moral adequacy and identity work as a carer demands the acceptance of the present. Her parents are in the present, at home, and currently have their essential physical needs met. My following “mm” works to acknowledge this but it does not claim agreement with Jane’s identity work, in this instance it is a “neutral monitor” of talk (Gardner 1997).

Summary of participant issues (Jane)

There was challenges with complex decision-making involving cancer treatments.

There was a lack of opportunity to engage with health professionals in order to explore more fully, the side effects of cancer treatment.

There was clear ethical dilemmas surrounding quality of life.

There was challenges with assessing mental capacity and conflict between carer and relative which made navigating the cancer treatment journey safely potentially problematic.

4.6 Betty's story

"They kept telling me he was doing well."

Betty, in her 70s, had lost her partner 4 years ago to both prostatic and oesophageal cancer.

Her speech was slow and methodical, and initially she framed her narrative within the context of the author of a letter she presented to me from a local newspaper. The letter, titled 'Dad's cancer care is just not good enough', described the story of a man who had delayed treatment for a rare form of cancer. He deteriorated rapidly with significant weight loss and depression to a point where surgery was inappropriate. The teller presented his father's journey as involving many health contexts but with no one offering active treatment. Only at the point of near death was he admitted for "full time medical attention". The teller left the story unfinished with his father waiting for an ambulance in the night. The coda of the story involved better co-ordination of care in diagnosis and treatment of cancer. Betty was to return to this letter throughout our dialogue as a point to

remember – *“it was like reliving part of my experience”* – and to reinforce the coda surrounding co-ordination of services as Betty comments: *“they just do not seem to be able to integrate, even now ... err if that letter says anything because I thought it would improve by now but it doesn’t seemed to have done”*. Betty categorised hospital care as focused on either physical or mental health and presented the problems as a consequence of the inability of formalised care services to address both needs simultaneously.

Her narrative, unlike Jane’s, appeared fixed on a small number of events that she (re)interpreted throughout the interview. Norrick (2010) refers to repetition as a common feature of narrative construction and a device used for a number of reasons including for dramatic effect or to highlight evaluation. Whereas Jane’s narrative was filled with uncertainty, in flux and open to multiple side-shadowing (Ochs & Capps 2001), for Betty the years had solidified a series of painful events and appear to present ‘atrocities stories’ (Stimson & Webb; 1975). These stories present criticism of how a doctor (and by extension a health professional) did behave to show how they should behave. As Stimson & Webb (1975) comment, *“those who see themselves as relatively powerless in a situation can redress the balance by stressing their own human and sensible qualities as against the comic qualities or stupidity of the more powerful, in this case the doctor”* (P107). An example of this positioning was evident in the following extract relating to the physical deterioration of her partner following surgery for his oesophageal cancer:

- | | |
|-----------------------|---|
| 1 Betty: | I tried to get him to go in a scooter |
| 2 | because his legs had gone |
| 3 Interviewer: | ok |
| 4 | ok |
| 5 Betty: | I |
| 6 | I think it was because he wasn’t eating |
| 7 | but err |
| 8 | to this day |

9 I don't know [why]
10 **Interviewer:** [mm]
11 **Betty:** his legs
12 and I was having (1.0)
13 to go the doctor
14 I was having to put him in a taxi
15 with the taxi driver
16 err
17 err
18 helping me
19 the doctors busy telling me how well he's doing
20 I'm telling the doctor "*no*"
21 he's going *down*
22 the hill
23 no he isn't.
24 I said he's losing weight
25 I said he's not eating
26 and of [course]
27 **Interviewer:** [why did the doctor] think he's doing well?
28 **Betty:** I don't
29 I know?
30 **Interviewer:** what measure was he using
31 to say he was doing well?
32 **Betty:** I don't know?
33 no {high pitched voice}
34 no
35 no
36 he just said *ooh*?
37 he's doing fine
38 and the
39 err
40 nurses who were coming
41 you know
42 they came once a week
43 **Interviewer:** ok
44 **Betty:** and they were busy informing me
45 how well he was doing
46 I said to them
47 he is *not*
48 he's lost
49 a great deal of weight
50 I said he's falling
51 err
52 you know
53 he's falling
54 you know
55 all over

In this interaction Betty presents and establishes her identity as a carer in attempting to address the symptom her partner is experiencing. Her use of 'gone' conveys the serious nature of his mobility issues and after my acknowledgement token Betty tentatively asserts that his nutritional needs could be the causal link to his immobility. She could present no clear link and further implies that no one has addressed why her partner's legs have 'gone'. One more question to the list of unanswered questions Betty asks to the audience within her narrative. Following my continuer 'mm' Betty presents an atrocity story (Stimson & Webb; 1975) in which she reaffirms the problem with her partner's legs but situates this outside of formalised care with the taxi driver having to help. Betty remains an outsider and she further extenuates this by describing a doctor talking at her and contesting her identity as a carer by challenging her judgement about how her partner was progressing. Betty positions this challenge through direct reported speech presenting her question to the audience: how can this doctor not see the reality of the situation? The significance of atrocity stories is the way tellers construct moral character and present the rationality of their actions (Baruch 1981). Betty accomplishes this by appealing to the reasonable standards of the everyday world that she assumes are shared by the listener. I support Betty's position by presenting a question about the doctor's judgement: Betty could not give a reasonable justification for such a view. I further probe this, looking for clinical competence through speculating about what criteria the doctor used. Betty responded, her intonation was high-pitched, expressing exacerbation at such an unfounded response from the doctor: she positions the absurdity of the medical claim "he's doing fine", inviting agreement from the audience after the catalogue of troubles she has already conveyed.

Betty extends the scope of this 'absurd' claim to community nursing staff who again contest her identity as a carer. She presents the limited contact they had with her partner but positions the nurses as 'busy' talking at her following the same script as the doctor. Betty again, through direct speech quotation, challenges this, emphatically rejecting this interpretation, and presenting to the audience the same reasons addressed before and extending this to describe the consequence of his legs 'going' with frequent falls. She speaks in the I/we voice occupying the 'carer' reality and remains the story teller as opposed to 'they' who belong to the 'medical' reality but who are absent from the encounter in which these stories are being presented.

Betty described the process of her partner's deterioration coupled with an ineffectual response from health professionals. Within her narrative she (re)-presents the same consistent approach to health professionals, articulating the issues of concern including weight and mobility loss and pain. She implicitly asks the audience: what would you do? and she positions her speech to catalogue the alternative answer from the health professionals. When a consultant decides to admit Betty's partner the narrative moves to further atrocity stories within an inpatient setting, highlighting the constant moving within the ward and the shouting of staff, and culminating in the abrupt disclosure of a terminal diagnosis. Her partner was moved into a side ward and the story moved towards discharge planning as the events unfolded. Betty was not in a position to adequately care for her partner at home and she did not want him to go into a care home. The dialogue continued:

- | | |
|-----------------------|---------------------------------|
| 1 Betty: | I wanted him to go in a hospice |
| 2 Interviewer: | mm |
| 3 Betty: | <i>Hospice</i> |
| 4 | I said |
| 5 | Yeah |
| 6 | I said hospice |

7 I said
 8 you've told me
 9 he's not going to last for 6 month
 10 **Interviewer:** mm
 11 **Betty:** I said
 12 he's in a great deal of pain
 13 I said
 14 care homes won't
 15 deal with that at all?
 16 I said that
 17 **Interviewer:** mm
 18 **Betty:** that's not what they're there for
 19 **Interviewer:** mm
 20 **Betty:** Well that's going to take a long time
 21 Well
 22 I said
 23 I want em in an hospice
 24 I said
 25 I can't look after him
 26 to the extent that he needs
 27 I said I can't
 28 **Interviewer:** mm
 29 mm
 30 **Betty:** I can't bathe him
 31 or
 32 do
 33 I said
 34 you know
 35 as I say
 36 incontinence
 37 err
 38 before he went into hospital
 39 where I was having to
 40 wash him
 41 and
 42 you know
 43 sort of clean the bedding
 44 **Interviewer:** ye-es
 45 **Betty:** at least once a night
 46 I was having to
 47 **Interviewer:** right
 48 ok
 49 **Betty:** to do that for him
 50 and [err]
 51 **Interviewer:** [did you get any support]
 52 with that symptom at all?
 53 **Betty:** no

54 **Interviewer:** nursing
 55 No
 56 ok
 57 **Betty:** nothing
 58 nothing
 59 all they were interested in
 60 was the cancer of [the]
 61 **Interviewer:** [ok]
 62 **Betty:** throat
 63 and err
 64 so I went home
 65 next day I got a phone call
 66 you better come (1.0) quick.
 67 and he died the next day
 68 **Interviewer:** gosh
 69 **Betty:** after they were telling me
 70 they were going to discharge him

Betty asserts her identity as a carer by specifying the discharge destination she wants and following my acknowledgement token 'mm' she quotes direct speech from the nurse: HOSPICE! The nurse is positioned in opposition to such a choice and Betty reaffirms this choice and justifies such an assertion by quoting the time frame she was given by a doctor. Betty further justifies to the listener her rationale for hospice admission by referring to uncontrolled symptoms and asserting that alternative formal care could not address these issues. She has positioned herself as someone who was aware of and competent to make a judgement of current formal service provision(s), indicating that care homes cannot manage uncontrolled symptoms. She further presents this dilemma to the listener, she maintains moral adequacy by acknowledging the complex needs that she cannot meet and asks what would you do? She "can't look after him" so what reasonable alternative could be offered other than a hospice? I acknowledge this with "mm-mm", with a flat slightly falling intonation indicating understanding with nothing substantial to add (Gardner 1997). Betty further positions herself as morally adequate by justifying her inability to physically care for

her partner, citing bathing and incontinence and the consequences of managing those issues to her. I seek clarification about whether she received support and after the emphatic “no” I specify nursing to which she reiterates the facts of no involvement. Betty then moves to an explanatory assertion that this is directly attributed to an exclusive concern of her partner’s throat cancer negating her narrative and identity work as a carer involved in the issues she has already articulated. She presents this ‘flattened’ restricted narrative of health professional concerns, and this is often extended to those actors involved. This device of portraying someone as a flat character allows Betty to have much more control over the plot and the moral of the story: the characters are fixed and finalised (Mattingley; 2010). Betty then proceeds to present a ‘flattened’ narrative, giving a short sentence in episodic structure sequencing from going home to her partner’s death. The suddenness of the event is represented and performed by the suddenness of the narrative positioned by Betty. My empathetic token reflects the impact of this narrative device. Betty’s evaluation represents another atrocity story, she asks the listener, how can these health professionals be so wrong in this evaluation/assessment?

Betty’s identity as a carer was contested throughout the stories she presents and this included her own partner. Betty describes situations where she was unsure whether her partner had had cancer or treatment: for example, she found a letter from an oncology centre that confirmed prostatic cancer rather than through any communication with her partner. In relation to treatment, her partner was going to have radiotherapy; however, Betty presented the ambiguity surrounding this since it became unclear whether he had treatment or not as this dialogue suggests:

1 Betty:	so that was the first I knew
2	and then we came home

3 and he
 4 he went to
 5 back to {name of cancer centre}
 6 and they did all the measuring
 7 and all the rest of it
 8 and
 9 errm
 10 he went once
 11 but
 12 you know
 13 I went with him
 14 err
 15 and after that he didn't go again?
 16 He didn't
 17 **Interviewer:** mm
 18 **Betty:** err
 19 and he kept saying
 20 oh I've been
 21 I've been
 22 (2.0) and
 23 err
 24 to this day
 25 I don't think he had been
 26 **Interviewer:** oh
 27 not at all
 28 **Betty:** not at all

In this dialogue Betty presents the process of cancer treatment and indicates the appropriate preparation required. This identifies her expertise in this area and justifies and gives authority to her following puzzlement. She presents the fact that he only went once and queries this to the listener, can this be right, does this make sense? Betty checks on shared views to affirm her fears with the forward-looking discourse marker "you know" (Schourup; 1985, Schiffirin; 1987) and further catalogues the sequence of events indicating the only occasion she knew her partner went since she was the witness. Betty quotes direct speech from her partner indicating his response to her questioning and then challenges this assertion and in answer to my question gives an emphatic evaluation of this narrative, "not at all".

Betty positioned confidentiality by health professionals as a threat to her identity as a carer affecting her actions to accomplish this performative accounting of care. She presented the example of not being informed what medications her partner was on in spite of his dementia because of issues of confidentiality. However, she was, by default, responsible for giving those medications at home. Without the legal recognition of marriage, a relationship lasting 26 years was positioned by Betty as of limited significance within the healthcare encounter. This can be contrasted by Betty's narrative about her own health in which she described the response of her consultant:

1 **Betty:** but I was under the same
2 err
3 specialist
4 and he advised me
5 not to have it
6 the operation I needed
7 because I'd need all my strength
8 to look after Greg

Betty attributes this vocational call and commission from the consultant and positions her essential, primary identity as a carer with medical endorsement. She presents self-denial as the morally adequate response to her partner's health issues but also highlights the difficulties that contest this identity through inappropriate applications of confidentiality and poor communication within formalised health services.

Summary of participant issues (Betty)

There was challenges with assessing mental capacity and conflict between carer and relative which made navigating the cancer treatment journey safely potentially problematic.

There appeared a lack of training for health staff surrounding dementia with a priority for physical health rather than mental health problems.

There was significant issues with health professionals involving the participant in care decisions and keeping her informed of treatment planning.

4.7 Lynne and Alan's story

"they took things at face value."

Lynne, in her 50s, was a carer of her brother, who had vascular dementia and been diagnosed with lung cancer. Lynne came from a large family but she and her sister were the main support for her brother. Her brother had four children, although he lived a 'troubled' life and had lost contact with all of them. Alan was Lynne's husband. Lynne started the interview in her back garden and was subsequently joined (unplanned by interviewer) by her husband who was keen to contribute to our discussion. Lynne consented to Alan's involvement and Alan had already read the information sheets sent to Lynne. I then got informed consent from Alan. This gave Alan official 'permission' to be involved creating legitimacy for his co-telling. In terms of impact on the interview Ochs & Capps (2001) suggest that narratives of personal experience within formal interviews often demonstrate low levels of co-telling with minimal feedback from the interviewer. The presence of Alan meant that as an 'interlocutor' he can draw into an active co-telling when the primary story

teller, Lynne, asks for help, even though it is not strictly necessary. This became a feature of the interview as it progressed. The analysis of a third participant was not substantially different to a primary interview with one teller and listener, the positioning of a co-teller and how we each change from teller to listener, to co-teller forms the primary interest within performative narrative analysis. How Lynne and Alan position themselves to the stories they tell provide the context for the underlying narrative genres they both use.

Lynne and Alan related stories concerned with care both at her brother (in-law)'s home (he lived alone) and within a hospital setting. Lynne begins the interview describing how her brother developed dementia after losing his wife. His lung cancer was diagnosed by a routine chest x-ray and Lynne indicated that it had "only just started". Lynne relays the trouble involved with her brother's radiotherapy and his apparent refusal to attend the daily appointments. Since he refused to go with the ambulance, treatment was left and Lynne presents the response from the consultant at the memory clinic:

- 1 **Lynne:** so they left it
- 2 and err that was
- 3 err
- 4 in January
- 5 now nothing was done
- 6 nobody come to see him
- 7 not his cancer nurse
- 8 nobody
- 9 it just seemed
- 10 he doesn't want it
- 11 that's it
- 12 **Interviewer:** Right
- 13 **Lynne:** and I thought
- 14 he's still got the cancer
- 15 **Interviewer:** yeah, absolutely
- 16 **Lynne:** err
- 17 and when we went the memory clinic in
- 18 (2.0) March I think it was
- 19 (2.0) April
- 20 no April it was

21 when we went back to the memory clinic
 22 she just had to say how
 23 how is he getting on about his lung cancer?
 24 I said nothing
 25 I said he refused treatment in January
 26 and nothing's been done
 27 She said you are joking?
 28 I said no
 29 She said
 30 do these people not understand that his got memory problems?
 31 and he's not
 32 you know
 33 somebody else should say
 34 I said I've been trying that
 35 I said
 36 since they stopped
 37 I said even the cancer nurse has never been
 38 and inquired
 39 and his still got the cancer
 40 why isn't the Macmillan nurse coming round
 41 and seeing him?

In this interaction, Lynne presents an atrocity story: the inactivity from formalised cancer services, nothing was done, nobody came, and she positions a specific health professional for culpability, the cancer nurse specialist. Lynne then presents her assessment of the reason for such inactivity, that of patient choice: her brother refused. After my acknowledgement token Lynne confirms to the listener the serious nature of her brother's condition. She is asking the question, can this be right, he has cancer? Lynne then presents an interaction at the memory clinic in which she lets the audience know the time frame in which no treatment had been implemented. Through the use of quoting direct speech she reiterates the story so far to the consultant and through her response creates a device to position a commonsense response to this situation: "do these people not understand that his got memory problems". The use of this device contests and challenges patient choice in the presence of cognitive impairment. Lynne maintains moral adequacy by letting the audience know she has tried, she has worked hard to accomplish her identity as a carer in

spite of limited support. Lynne returns at the end of this interaction to the cancer nurse and again ask the audience: why has the nurse not she seen her brother?

Lynne presents the memory clinic consultant as the catalyst for a change and the reason her brother subsequently had cancer treatment. Her narrative highlighted the face-value acceptance by health professionals of much of what her brother said without a realistic acknowledgement and assessment of his capacity to make informed decisions. Both Lynne and Alan present the difficulties of trying to convey the reality of the situation, whether to staff from the memory clinic or within the oncology centre. Lynne presents almost comic stories (with her laughing within the dialogue) as she attempts to mouth behind her brother's back in contradiction to his assertions within clinic appointments. Trouble-tellers laugh to show "troubles-resistance" (Jefferson 1984) and Lynne brings the coda of this story to the fore:

1	Lynne:	And I'd walk out
2		and I'm thinking should I go back
3		and explain
4		and I think they must know
5		but they just ask him questions
6		you know
7		and take it as face value
8		and I think it's not right
9		why are they asking him
10		they should be asking me
11		or saying
12		could you come back in
13		or something

Lynne presents the threat to her identity as a carer: how can she support her brother if health professionals do not acknowledge the dementia? She asserts a moral challenge by claiming this is "not right" and asks the audience to address the question, why are they not talking to her? Why are they contesting her carer identity? Lynne proceeds to engage in

further story telling demonstrating her brother's poor short-term recall when assessed by health professionals. In spite of these stories the underlying narrative discourse from both Alan and Lynne was attempting to present the question: why did Lynne as his carer appear to be relegated to the clinical 'borderlands' of care (Mattingley 2010)? Alan introduced a discussion on the fluctuations in quality of formalised care staff, and this narrative thread was underpinned by a moral imperative to proactively support his brother-in-law. Alan had entered the discussion at 19.28 minutes after the start of the interview (with the permission of Lynne) and would often reiterate and expand on the narrative that Lynne had already articulated. Alan presented the situation where his brother-in-law would eat once food was placed in front of him but if asked would decline or refuse. He then describes and gives an example of a good carer, presenting Peter who made sandwiches without asking. Alan contrasts this with poor care, where a carer just writes in the notes 'declined food' with no follow-up. The evaluation of this story was presented with a situation where his brother-in-law might not eat for 24 hours.

In similar vein to Betty's and Jane's narratives, Lynne presents the challenges to her identity as a carer from the person living with dementia, in this case her brother. She describes to the listener the refusal of her brother to have installed an electronic key holder so carers could get access if he was incapable of opening the door. Lynne presented the situation of carers asking her whether they could force entry to see if he was safe. She positions herself as care co-ordinator and told the carers to avoid this since he was probably asleep, presenting boredom as the root cause of his tiredness. This 'hidden' work as a carer added to the burden since her brother, whom Lynne presents as unaware of both his dementia and, at times, the cancer, contested her caring role. Lynne acknowledged that her brother

was “very obstructive and nasty” even before the dementia, and of her large family only she and her sister engaged with him.

Both Lynne and Alan present a situation of ‘benign’ neglect within the context of hospital care. Accepting things at face value fails to address the complex and personalised needs of her brother or to acknowledge the communication issues that are inherent within dementia care. Lynne and Alan present a story related to personal care, and this story contains the elements routinely used within the complex genre of narrative, including description, chronology, evaluation and explanation (Ochs & Capps 2001).

- 1 **Lynne:** I’ll give you one for instance
2 whilst in hospital
3 he had his jeans on
4 he got dressed in the morning
5 had his jeans
6 and a top on
7 and err
8 he still had them on the next day
9 he’d slept in
10 erm
11 **Interviewer:** Right ok
12 **Alan:** so somebody’s
13 it shows to me
14 that nurses are not been too
15 he still slept on top of the bed
16 all night with his
17 [nobody]
18 **Interviewer:** [why do you think] that is
19 w-w-hy
20 why do you think
21 they wouldn’t have gone towards him
22 do you think?
23 **Alan:** I don’t know
24 they could have even asked him
25 to get changed
26 and he might not
27 and they left him to it
28 you don’t know
29 you think it’s one thing they would do
30 **Lynne:** it was after a couple of days

31 one of the nurses said
 32 to our Sandra [sister]
 33 when she went to see him
 34 err
 35 does he need prompting
 36 to have a wash
 37 because he's not had a shower
 38 for two week
 39 **Interviewer:** right
 40 god
 41 **Lynne:** and
 42 err
 43 Sandra said to him
 44 he needs a shower
 45 and they said
 46 it's only there
 47 well they need someone to go
 48 and put it on for him
 49 **Interviewer:** yes
 50 **Lynne:** because anything mechanical
 51 he can't
 52 he doesn't know
 53 **Interviewer:** yeah
 54 yeah
 55 yeah
 56 **Lynne:** I said
 57 they need someone to go in
 58 and put the shower on
 59 and tell him to go in

Lynne presents a story preface in which she informs a hearer about what a story involves so the hearer is able to gauge when the story is over (Sacks; 1968). Lynne sets the scene, locates this 'atrocious' story and presents the issue of her brother sleeping in his own clothes. She confirms these events to the listener by specifying the type of clothing, the time he wore them and her witness to the same clothing the next day. This led Lynne to argue the case that "he'd slept in em". After my acknowledgement token, Alan interjects by presenting this chronology of events as evidence that no one has observed his brother-in-law and then specifies this to nurses in particular. He further conjectures to the audience

that he slept on top of the bed, his clothes visible and thus compounding the moral culpability of the nurses. I interrupt Alan by a question, seeking clarification. Conversational narrative routinely involves questions, clarifications, challenges and speculations about what might possibly have happened (Ochs & Capps; 2001). This question is not neutral but demands from Alan an answer as to why his assertion that staff were avoiding his brother-in-law would be the most appropriate interpretation. Within stories the critical issue becomes the assessment of the relative plausibility of an interpretation when compared with other specific and potentially plausible interpretations (Mishler; 1986). This question is taken up by Alan, who initially positions the staff in a more positive light with an assertion that they may have possibly requested his brother-in-law to get changed. It is also followed by an acknowledgement of the conjecture about staff motivations with “you don’t know”. Alan, however, then reaffirms moral culpability by asserting that the staff should have noticed, and Lynne interjects and develops this story with her description of an interaction between her sister and the staff. Lynne, through quoting direct speech, positions two reported comments by staff to the audience to demonstrate moral culpability. Lynne seeks affirmation from the listener as to the commonsense understanding that if her brother has not had a shower in two weeks it is highly likely that he needs prompting. Following this I give an empathetic acknowledgement token, “right, god” and Lynne proceeds to describe how her sister had to reassert her identity as a carer by articulating what the health professionals need to do. Lynne defines the problem with the bathroom equipment and offers the solution (changing the ownership of the solution from her sister to herself with “I said”) by demonstrating how to use the shower and prompting him to go in.

The issues related to access to treatment were broached by Lynne and Alan and they describe the reasons why their brother (in-law) could not have treatment as an outpatient. In particular, they present his erratic sleeping pattern, meaning he would be asleep when the ambulance arrived. The discussions with the consultant occurred after the medical team at the memory clinic responded to the delay in treatment and contacted the oncology team. Alan had previously positioned the oncologist as concerned with the non-compliance of his brother in-law and the subsequent financial cost of this planning of treatment. Alan and Lynne present the discussion with the oncologist in an outpatient setting:

1 Alan:	I said
2	there's no one to get him ready
3	if an ambulance comes
4	he could be in bed
5	I said
6 Interviewer:	so Doctor Smith was saying
7	the cost is the thing
8 Alan:	yes
9	and he wouldn't bring him in
10	and then he said to me
11	he said
12	I said
13	why won't you bring him in?
14	he said
15	I only bring people in
16	who are very ill
17	and I said
18	you're joking
19 Lynne:	cancer {laughing}
20 Alan:	I said
21	do you know what you've just said
22	Now
23	he had four people with him
24	and I said
25	do you know what you've just said
26	err
27	so you're saying cancer's not a serious thing
28	I, I {indignant voice} didn't mean that
29	Yes
30	but you've just said that

31 I said
 32 I'm trying to tell you
 33 it's his dementia
 34 you know
 35 **Interviewer:** yeah
 36 **Alan:** it's not his fault he wouldn't come every day
 37 you could start off with 20 treatments
 38 it's a lot
 39 With somebody knocking on his door
 40 even now
 41 he has a problem with carers getting in
 42 or when we go to see him

In this dialogue Alan presents the problem: his brother in-law lives alone and may not be ready when transport arrives. He accounts for his carer identity by presenting these issues to the listener. I interject after reflecting on the previous discussion and ask a question related to financial cost, I want to explore further reasons touched on before. Alan confirms this interpretation implying that cost is the reason for not admitting his brother-in-law and anatomises the dialogue, presenting a blow-by-blow account using direct speech quotation of the interaction with the consultant. Alan maintains moral adequacy by presenting this question to the audience: having experienced the problems before, the commonsense answer would surely be to keep his brother-in-law as an inpatient. Alan positions the consultant's response directly after, implicitly contesting the extent of the trouble with the assertion that only the "very ill" should be admitted. After challenging this position with "you're joking", Lynne interjects and presents the word "cancer" to the listener. She laughs, reinforcing and demonstrating the absurdity of considering people with cancer as not very ill. By quoting direct speech, Alan establishes witnesses to the moral claims invoked by the consultant's position. He (re)-presents the statement back to the listener and seeks further confirmation that cancer is "not a serious thing". Alan positions the consultant as 'back

tracking', animating the dialogue phonetically, imitating the consultant's indignant assertion "I didn't mean that". The evaluation and subsequent coda of the story then follows, with Alan positioning the dementia as the unacknowledged context that demands inpatient treatment. After my acknowledgement token he further explores the context and impact that his brother in-law's dementia to the listener, examining the complexes of accounting for care. Both Lynne and Alan are attending to what Baruch (1981) describes is "*the issue of their acceptance as moral persons, competent members and adequate performers. Hence, in formulating their accounts, they accomplish the status of moral adequacy*" (p276).

Alan reiterated his concerns with health professionals not including his wife in any care decisions and his narrative(s) often revealed the consequences of this exclusion. Contesting their identity as a carer affected compliance with treatment for their brother(in-law) and also led to insensitive care management, with multiple agencies sending 'strangers' into Lynne's brother's house causing more confusion. Both Lynne and Alan conveyed the impact of maintaining their identities as carers, with Alan dealing with his own health concerns (living with COPD) and Lynne having recently been in hospital as well as surviving breast cancer. The financial and time burden was also significant, involving taking their brother (in-law) to frequent appointments to multiple clinics. This related to both the cost of petrol and the inordinate amount of time spent waiting in outpatient departments or getting appropriate medications from pharmacies. In co-ordinating care Lynne and Alan had to navigate formalised care and often rearrange appointments that were inappropriately timed. There was, as with Jane's story, an element of despair within their narrative as Alan comments:

- 1 **Alan:** you know
2 and you just think

3 where are we going
4 like
5 cos
6 I can't see it going any better
7 and what's the alternative
8 put him in a home
9 which we don't want
10 we wouldn't want him
11 in a home

To maintain moral adequacy requires his brother-in-law to stay at home but this is becoming more precarious as their identity as carers is contested. The maintenance of meaningful hope becomes problematic as the toll of care becomes more burdensome. At the termination of the interview I asked Lynne if she would record a diary for a week to record any further thoughts and she sent back a handwritten note:

"Just come back from seeing Bill. He has started smoking again, so now he is not eating properly again. There's nothing else to report except there have been no contact from social service or McMillan Nurse."

Lynne conveys through 'trouble-talk' the blow-by-blow sequence of events that have subsequently developed. Smoking and nutrition are now issues and this is posited before a statement about the non-engagement by nursing and social care. There is "nothing else to report" since the problems and demands of care are constant and immediate with the only variable related to formalised care response and provision.

Summary of participant issues (Alan and Lynne)

There was significant issues with health professionals involving the participants in care decisions and keeping them informed of treatment planning.

There was challenges with assessing mental capacity and conflict between carer and health professionals which made navigating the cancer treatment journey safely potentially problematic.

The cancer centre did not assess mental capacity appropriate and appeared inflexible in adapting treatment pathways to meet the needs of someone with cognitive impairments.

Ward based staff appeared not to assess or address the person-centred needs of the participants relative.

Participants positioned stigma/discrimination as an issue.

4.8 Lauren's story

"If you get someone there who knows what they're doing and has a bit of care for human beings the difference in your appointment is incredible."

Lauren is in her 50s and is a nurse with two elderly parents, both with dementia. Her father has had a number of previous cancers but bladder cancer was diagnosed when he also living with dementia. Lauren's mother had more advanced dementia and Lauren placed her dad about 4 years behind her mum in terms of the severity of the condition. Our interview took

place in Lauren's home, which she now shared with her mum. Her parents had been divorced a number of years ago. Her dad still lived independently within the locality; his bladder cancer was treated conservatively with localised chemotherapy rather than surgery and hence her experience as a carer was often situated within the context of outpatient clinics. Lauren presents the difficulties of choice and information giving. This was within the context of supporting her father, someone who is cognitively impaired, and how this process could be managed in order to maintain her position as a carer. She views this process as complicated by her identity as a nurse and the subsequent expectations her father placed on this identity. Lauren's dad insisted that she interpret the medical information they were given (either oral or written) even if she felt unsure as to her competence in this medical field. Since he could not retain this information and at times actively disputed her interpretation of medical consultations this became a source of frustration and conflict with her dad. Lauren presented a consultant who proactively offered a CD recording of the consultation so she and her dad could refer to it. She highlights to the listener how helpful this is, as Lauren's dialogue suggests;

- | | |
|------------------------|---|
| 1 Lauren: | and actually as a carer |
| 2 | it meant that it wasn't |
| 3 | my job |
| 4 | then |
| 5 | to keep interpreting what the doctors said |
| 6 | my other problem is |
| 7 | because I'm a nurse |
| 8 Interviewer: | mm |
| 9 Lauren: | even though |
| 10 | all my work has always been in palliative care |
| 11 Interviewer: | ok |
| 12 Lauren: | and I keep pointing out that all my patients died |
| 13 | I'm not the best person |
| 14 | to ask about stuff around that |
| 15 Interviewer: | yeah |
| 16 Lauren: | he continually asks me questions |

17 and expects me to know loads of stuff
18 that I just don't know

Lauren positions herself as primarily a carer and presents her expectations of what this carer identity should exclude within this 'job': the interpretation of biomedical information given by doctors. Lauren associates these extra interpretative responsibilities as problematic and related to her identity as a nurse. After my discourse marker 'mm' Lauren specifies her area of expertise within palliative care and presents her patient outcomes to the listener in order to position and support her claim to ignorance and maintain moral adequacy in the face of her dad's expectations. After my acknowledgement token Lauren presents her evaluation of the situation with particular focus on the repetition of the discourse with her dad. Lauren describes her dad's denial of his cancer, the distress that repeated cystoscopies caused him and the subsequent urgency he developed post treatment. In her narrative she also relayed problems with outpatient department, and this became a repeated feature in our dialogue as the excerpt below indicates:

1 **Lauren:** we then
2 were told by the doctors
3 we went back
4 and had an outpatient appointment
5 and I have to say
6 that going to outpatients
7 with either of my parents
8 with Alzheimer's
9 is a step into Dante's inferno
10 quite frankly
11 **Interviewer:** ok
12 what
13 w-what way?
14 **Lauren:** err
15 the clinics are not organised
16 around anyone with Alzheimer's
17 they don't seem to understand
18 that people are confused
19 anyway

20 but that
 21 if you're got someone with confusion
 22 some of it is terrifying
 23 **Interviewer:** yeah
 24 **Lauren:** they have this whole thing
 25 of calling people
 26 at all the clinics
 27 particularly the eye clinics
 28 is my big
 29 I hate
 30 **Interviewer:** yeah
 31 **Lauren:** clinic
 32 err
 33 where they just walk in
 34 shout a name
 35 and then walk out again
 36 and for somebody who's a bit confused
 37 they spend their whole life
 38 both parents
 39 going
 40 was that me
 41 was that me

Lauren presents the story preface (Sacks 1968) and proceeds to announce the 'trouble-talk' with her pre-emptive evaluation of the event, "*a step into Dante's inferno*". She positions her judgement to a more generalised experience of dementia by including both her parents.

This invites me to ask, following my acknowledgement token 'ok', the continuer 'why'.

Lauren presents a statement articulating organisational problems with people living with dementia referring to 'they', characterless 'others' representing a medical world, personally absent from the encounter but the impact of their system(s) resonating and contesting identity production within the clinical encounter. Lauren further positions herself through presenting the emotions of someone living with dementia, (universalising the experience of her parents) from feelings of confusion to being terrified. She then specifies an example to illustrate her statement(s), the eye clinic and the action that she 'hates', the calling of patient names. After my acknowledgement token 'yeah' Lauren details the action, further

operationalising the process with somebody walking in, shouting a name and then exiting. She then positions the audience to examine the impact of someone with cognitive impairment (generally and then citing her own situation specifically) of this clinic process through direct speech quotation of her parents' "was that me, was that me".

Lauren describes the subsequent introduction of an electronic sign-in for outpatients at her local hospital and presents this and hospital signage as examples of the environment and processes that militate against those with cognitive impairments. Lauren further positions the environmental and structural architecture of the hospital as particularly challenging with different levels and entrances with the memory assessment unit situated at the back of the hospital in a separate building. Lauren presents these problems and then reveals her dad's reaction to them as a device to highlight the impact to the listener. Her dad had appointment letters indicating he is to give it to the receptionist so he did not understand why there is an electronic system that contradicted this request. He constantly (re)-checked a hospital map because he was lost and required continual reassurance in order to manage his anxiety. There were also issues with medical staff insisting on a medical and medications history from Lauren's dad that he found upsetting and challenging on two accounts. Firstly, it would be in the medical notes so why had the doctor not read them, and secondly, with a cognitive impairment this immediately created potential stigma by asking questions he could not address. The dialogue moved to the medical consultation surrounding histology results, and Lauren presents the dilemma posed by the prospect of major surgery:

- | | |
|-----------------------|-------------------------------------|
| 1 Lauren: | so we went back |
| 2 | to see the consultant |
| 3 | to get the results of the histology |
| 4 Interviewer: | yeah |
| 5 Lauren: | and she gave us the results |
| 6 | and started talking to him |

7 about
 8 having his bladder removed
 9 **Interviewer:** right
 10 ok
 11 **Lauren:** and at this point
 12 I just looked at her
 13 and went
 14 (2.0 pause) he's 82
 15 **Interviewer:** right
 16 **Lauren:** he's got
 17 he's on a spectrum
 18 towards dementia
 19 you're talking about giving him massive
 20 major surgery
 21 I don't think so
 22 **Interviewer:** yeah
 23 **Lauren:** I think your find
 24 **Interviewer:** gosh
 25 yeah
 26 **Lauren:** so
 27 I just went no
 28 at which point dad goes
 29 but I haven't had
 30 I don't know whether I want it
 31 or not
 32 and I said dad
 33 right
 34 and so all these things
 35 were starting to be discussed
 36 but the consultant only
 37 has
 38 so many minutes

Lauren introduces the story and sets the scene, specifying the context, a consultation and the reason, disclosure of histology results. After my continuer, 'yeah', she presents the chronology of events and specifies one treatment option that she positions as the focus of discussion; the surgical removal of her dad's bladder. Following my acknowledgement token 'right, ok', Lauren presents her position to the audience, building up to this point with her dramatic description of her action of staring at the consultant. After a pause, her dad's age was then presented as evidence to support her reservations. Lauren was attempting to

enlist listener agreement as to the absurdity of major surgery as 82. I present the continuer, 'right', and then she further justifies her position and moral adequacy by citing her dad's dementia as a variable that needs accounting for. Lauren reminds the listener of the extent of the surgery and directly presents her opposition: "I don't think so". After my acknowledgement token, 'gosh, yeah', Lauren reaffirm her position and then presents her dad's response through reported direct speech. She articulates the ambiguity through positioning her father's confusion to the listener – "I haven't had, "I don't know" – before she intervened in shutting down the reported dialogue with "right". Lauren then positions this widening discussion within the context of a time limited outpatient appointment. Lauren represents the communication challenge within this environment and further on in her dialogue questions the giving of treatment information without adequate tests on which to base those treatment decisions. Caring was accomplished in this dialogue by presenting the consequences of too much general information that her dad could not possibly retain given his cognitive impairment. Lauren's identity as a carer was also contested by the prospect of major surgery. Within her narrative she came back to this at numerous points, positioning the prognosis, his age and his underlying dementia as a central concern before any major interventions should be considered. She presented her evaluation as *"you have to look at the whole person, I do think that's missing in medicine"*.

Lauren's narrative often centred on information giving, and she presents her struggle at receiving specialist Macmillan nurse support in conveying appropriate information to her dad. She also focused on the trauma her dad experienced with any clinical encounter, for example the ward environment that was not perceived to be dementia-friendly contributing to her dad's incontinence and subsequent embarrassment. In a similar narrative to that of

the other participants, Lauren's identity as a carer was contested by the care recipient; her dad challenged and dismissed her attempts at managing the situation. This often led to "massive rows" and was compounded by health professionals whom Lauren presented as taking her dad's representation of reality without mediating his position in the presence of cognitive impairment. The following dialogue highlights the clinical interplay:

- 1 **Lauren:** and I think that's quite frustrating
2 for him too
3 **Interviewer:** yeah
4 I'm sure
5 **Lauren:** I know it is for mum
6 **Interviewer:** mm
7 yeah
8 I bet
9 **Lauren:** because I know on one hand
10 they can't be in charge
11 and on the other
12 it's taking some of their
13 and it is this constant play
14 I think
15 when you're there as a r-relative
16 it's a play with the doctors
17 that they're trying to take notice
18 of this person
19 quite rightly
20 **Interviewer:** yeah
21 **Lauren:** who has Alzheimer's
22 as though they're a person
23 it's a play with the carers
24 when the carers are being ignored
25 and at the same time
26 you have to get a balance
27 and it's a hard
28 **Interviewer:** [mm]
29 **Lauren:** [balance]
30 I think
31 **Interviewer:** mm
32 **Lauren:** to get right
33 so everyone comes out of the consultation
34 feeling like
35 we were all taken notice of

36 yes
37 it's a hard one to get right

Lauren presents her dad's emotional life to the listener, indicating his frustration, and, after my acknowledgement token, "yeah, I'm sure", she reaffirms this interpretation by associating it to her mum's emotional experience of dementia. I give a strong affirmation with "mm, I bet" and then Lauren presents a moral dilemma to the listener with an assertion related to self-care that implicitly situates her identity as a carer. She positions the difficulty of taking away autonomy and how moral adequacy can possibly be navigated under these circumstances. Lauren highlights the performative elements (Goffman 1959) of such interactions, suggesting, "It is this constant play" in relation to her role as a relative. She widens the actors in such a performance to include doctors who "quite rightly" need to take a person-centred approach with the patient living with Alzheimer's but Lauren also presents the need to acknowledge carer concerns which she intimates could be "ignored". She presents the balance that needs to be effectively managed and, as Mattingley (2010) suggests, within these clinical encounters Lauren can be positioned as a cultural broker in attempting to facilitate partnerships with healthcare professionals. Within this clinical borderline the stakes are high, and the moral imperative that Lauren positions so that *"everyone comes out of the consultation feeling like we were all taken notice of"* is a clinical border skirmish that requires a collective performance. As Mattingley (2010) comments, "In the world of clinical encounters, the patients or families are most obviously travellers in the 'exotic' land of the hospital, where they encounter unfamiliar languages, rituals and expectations about how to act their part" (p12).

Lauren presented two occasions when she complained about her dad's care to the listener. The first incident related to the communication skills of a consultant whom Lauren positions

as very rude, leading her to insist in clinic that her dad would not see him again. Within this story Lauren positioned a health support worker as an exemplar to highlight to the listener how effective communication should or can be demonstrated. By using this narrative device to contrast the two clinical encounters Lauren gives positive examples of attentive interactions with her dad, including proactive clinic updates when delays were occurring and the offer to unpack clinical information given by the doctors. Lauren then presents the coda of the story: *“if you get someone there who knows what they’re doing and has a bit of care for human beings the difference in your appointment is incredible”*. The second incident related to how her mum was treated, and Lauren presented her mum’s academic background as an Oxford scholar to preface and contextualise the story. Lauren initially presents the strategies her dad uses to manage his cognitive impairment, including making jokes, and then relates the story to the attitudes of others who treat him like an “idiot”. In the following excerpt Lauren describes a particular clinical interaction involving her mother;

- | | |
|------------------------|--|
| 1 Lauren: | err |
| 2 | but I’m about to get her |
| 3 | notes |
| 4 | and everything changed |
| 5 | to Dr Smith |
| 6 | because I’m <i>sick</i> of her being treated |
| 7 | as if she was got no |
| 8 | she’s no one |
| 9 Interviewer: | right |
| 10 Lauren: | I’m <i>sick</i> of it |
| 11 Interviewer: | yeah |
| 12 Lauren: | err |
| 13 | and I realised |
| 14 | when I heard one of the consultants |
| 15 | they |
| 16 | err |
| 17 | thought she might have breast cancer |
| 18 | at one point |
| 19 Interviewer: | right |
| 20 Lauren: | and I heard the consultant say |

21 I'm going next door
 22 to see the little demented lady
 23 **Interviewer:** ohhh [softly spoken]
 24 **Lauren:** and I just felt
 25 right that's it
 26 they're going to have to call her doctor
 27 I'm going to *make* the doctors call her doctor
 28 **Interviewer:** yeah [softly spoken]
 29 **Lauren:** I know no one else mostly cares
 30 but doctors take notice of that stuff

Lauren presents an action, she is going to access her mum's notes and then initiate a change in title to recognise her PhD academic status. Lauren directly associates this with how her mum is treated, and in particular the denial of personhood, with her comment, "she's no one". After my acknowledgement token, "right", Lauren expresses her frustration and grounds this emotional response by presenting an example to the listener to justify her position. The example specified a consultant and she prefaced the story within the context of potential breast cancer. Lauren positioned herself as overhearing a conversation and then through the device of reported direct speech presents the consultant's conversation, "I'm going next door to see the little demented lady". I present my non-lexical response "ohh", softly spoken, acknowledging the inappropriate comment and the impact of overhearing this dialogue. Lauren presents her response to such comments and attempts to position her mum as not 'other' but the same as the consultant treating her, "I'm going to make the doctors call her doctor". After my acknowledgement token Lauren positions herself as someone with 'insider' knowledge of the clinical environment with the comment "doctors take notice of that stuff", able to distinguish between different health professionals and specifically what doctors attach significance to. Lauren was attempting impression management (Goffman 1967) on behalf of her mother, and Knowles et al (2015) suggest there is a strong component of emotional work performed by carers, including biographical

work to help preserve the identity of the cared-for person. This can also derive from preventing subsequent disruptions to family relationships and the preservation of independence. Lauren is engaged in more subtle caring activities that can be defined as 'emotional' work. Lauren accomplishes the identity of carer by attempting a strategy (the positioning of her mum's PhD) to maintain moral adequacy in the face of stigma (Goffman 1963). In the presence of cognitive impairment, the disclosure of potentially stigmatising information can rest on carers' decision-making choices. So at times it was Lauren's choice "to display or not to display, to tell or not to tell, to let on or not let on, to lie or not lie and in each case to whom, how, when and where" (Goffman 1963; p57). Lauren has to make moral judgements as to whether to support her dad to 'pass' without disclosure and navigate clinical interactions in order to facilitate that. This can be challenging and, as Mattingley (2010) reminds us, "these travellers also confront the problem that they may appear unfamiliar or exotic to health professionals. Worse still, they may appear as 'familiar strangers', prejudged and slotted in categories where they are dismissed, invisible, neither known nor deemed worth knowing" (p12). Lauren had (re)-created an identity for her mother so she could be deemed worth knowing. and this remained her challenge in accomplishing caring.

Summary of participant's issues (Lauren)

There was significant issues with health professionals involving the participant in care decisions and keeping them informed of treatment planning.

There was challenges with assessing mental capacity and conflict between carer and relative which made navigating the cancer treatment journey safely potentially problematic.

Clinic based staff appeared not to assess or address the person-centred needs of the participants relative.

There was issues with stigma and dementia.

4.9 Helen's story

"You're fighting that person's corner."

Helen's interview was significantly shorter than the previous participants, with less "trouble talk". Her narrative presented a more supported treatment journey for her husband, who was living with Alzheimer's disease. Helen was in her 70s and lived with her husband Greg who remained present throughout the interview. He was diagnosed with soft-cell sarcoma after initial investigations for a deep vein thrombosis. He had an extended treatment journey including 4 surgeries and a 30-day course of radiotherapy. Helen (re-)presented the coda of her narratives with the repeated phrase "it was a good experience" and characterised and contrasted this with "blips" in her husband's care to which she storied her narrative. As Ochs & Capps (2001) comment, "Like scientists discerning whether an observation is an experimental artefact or a true discovery, tellers consider whether a set of events is ephemeral, a mere blip on the experiential record or whether it represents, like

the fall of the Berlin wall, a sea change” (p224). The blips Helen reported were sometimes related to the processes of clinical management or isolated individual failings by clinical staff to address her husband’s specific needs in the presence of cognitive impairment. An example Helen gives below relates to meal times in a ward environment:

- 1 **Helen:** to help me
2 not so much
3 it’s just
4 that’s
5 err
6 right
7 that’s another thing
8 that
9 that
10 that
11 that is funny
12 because
13 you know
14 they have
15 err
16 they’ll perhaps
17 have to have a menu for the next day
18 **Interviewer:** yes
19 yes
20 **Helen:** or they’ll come round and say
21 So
22 They came round there
23 **Interviewer:** mm
24 **Helen:** with the menu
25 and they’d say
26 err
27 to Greg if I’m not there
28 **Interviewer:** mm
29 **Helen:** right Greg what do you want
30 what would you like
31 and he’d start of
32 and the first thing he said
33 err
34 he’d say it’s fine
35 fine
36 and so he ended up
37 this was after a few days
38 we’d realised he’d had fish and chips {laughing} [every day]

39 **Interviewer:** [oh all right], because it was the first [thing] {laughing}
 40 **Helen:** [the first thing] they said
 41 so he immediately said
 42 yeah fine yeah
 43 and so very diff-
 44 of course
 45 I knew
 46 how to choose things
 47 so he'd get varied

Helen changes topic and introduces a different story, providing a preface and letting the audience know it is going to be “funny”. She relates a story about ward process in regard food choice and after my continuer “yes, yes” Helen presents her absence to the listener and the subsequent consequences of that absence. She uses direct speech quotation, first related to an unidentified person asking about choices and the second her husband’s response, which Helen characterises as a quick, immediate reply of “that’s fine, fine”. Helen laughs as she delivers the comic consequences of these interactions with Greg having fish and chips every day. I join in the laughter and surmise to Helen that it must be the first choice on the list presented to Greg. She affirms this and reinforces to the listener her identify as a carer by asserting how and what to choose for Greg. Helen, in her continued dialogue, presents her strategy of filling in the menu form in advance and positions herself as an integral part of Greg’s care requiring inclusion within any decision-making process. Helen’s narrative(s) present her strategies to maintain moral adequacy, and this was based on her own ability either to remain assertive or to effectively use specialist nurses, (either cancer or dementia) in order to facilitate appropriate care for Greg. In the following extract I initially enquire about Helen’s meeting with the dementia nurse, Sarah, and the dialogue unfolds below;

1 **Interviewer:** how did you meet Sarah

2 was that straight away
 3 or
 4 **Helen:** no
 5 it was just
 6 funnily enough
 7 she was actually
 8 cos she use to come up
 9 and see us
 10 to see [Greg]
 11 **Interviewer:** [ahhh]
 12 **Helen:** while we were at {name of cancer centre}
 13 and
 14 err
 15 she'd come up
 16 and
 17 erm
 18 and she'd see make sure
 19 we're all right
 20 and it just so happened
 21 it was that just
 22 that happened
 23 half an hour before she came
 24 err
 25 and she said
 26 is everything all right
 27 and I said
 28 ohh
 29 there was a young girl there
 30 who was
 31 err
 32 I am
 33 I'd gone to walk into a room
 34 where Greg was
 35 and Greg was on
 36 err
 37 the commode
 38 and she just shouted at me
 39 errm
 40 "go in the dayroom
 41 and wait" {laughing}
 42 didn't say
 43 who are you
 44 **Interviewer:** {laughing}
 45 **Helen:** you know
 46 **Interviewer:** right
 47 ok
 48 **Helen:** give me some privacy

49 and I was *absolutely* shocked
 50 you know
 51 so I went in the dayroom {participant's husband indicated that
 52 this was his wife the woman was speaking to}
 53 no she
 54 so anyway Sarah
 55 went
 56 and sorted it
 57 and she was all right after that
 58 she was fine
 59 err
 60 she just
 61 you know
 62 so instead of asking
 63 who are you
 64 because surely if you're a stranger
 65 and saw
 66 if you walked in a room
 67 and you saw someone on the commode
 68 and it wasn't your relative
 69 you'd go out anyway {laughing}
 70 **Interviewer:** yeah
 71 **Helen:** you say
 72 oh sorry {laughing}
 73 **Interviewer:** yes {laughing}
 74 you would
 75 **Helen:** you'd just back out (laughing)
 76 **Interviewer:** yeah
 77 absolutely (laughing)
 78 **Helen:** so
 79 it's just
 80 it's just little things like that
 81 but
 82 most of the time
 83 it worked
 84 most of the time
 85 been really, really good
 86 experience
 87 yeah

Following my question Helen indicated some existing contact with the dementia nurse and
 after my acknowledgement token "ahhh" Helen presents the supportive nature of these
 encounters. She then interjects with an event in which she anchors to a time frame related

to half an hour before the dementia nurse's visit. Through quoting reported speech Helen positions the dementia nurse to ask the same question the listener is also wondering about, "is everything all right?" Through this device Helen begins her story and introduces an actor, stressing her youth and following this she reveals the event, walking into a room whilst her husband was on the commode. Helen describes this person (a flattened actor without a job title) and lets the listener know she shouted at her to wait in the day room. This generated laughter indicating "troubles-resistance" (Jefferson 1984) and suggesting embarrassment, relaying to the audience the social inappropriateness of such a response. Helen also presents an atrocity story and tells the listener what this person should have said, asking her identify before shouting. I reciprocate the laughter and offer an acknowledgement token accepting her positioning of this event. Helen further presents her response to the event – "shocked" – and her husband supported this interpretation within our interview. Helen then switches focus to the activity of the dementia nurse, with Sarah resolving the conflict and thus positioning an unknown, young girl, a "flattened" actor, juxtaposed to a specialist nurse who maintained personal contact with Helen and Greg and knew the situation. Helen then positions the "commonsense" approach to this situation, characteristic of atrocity stories, and asks the audience who would enter that room if you did not intimately know them. This "young girl" should have known this and supported her identify as a carer like the dementia nurse had. After my acknowledgement token "yeah" Helen further indicates what you should say if you did not know a person on a commode, and our joint laughter intimates the embarrassment of such an event and the quick exit that should ensue. Helen finishes the story by minimising the impact to her wider interpretation of events, by indicating this was a "little thing", that it usually worked well and as such could be characterised as a "good experience".

Helen positions her late mother's care as a precipitating factor that led to her assertive behaviour. Her mother had mild cognitive impairment and was 97 when she died, and Helen recalled a health worker in the hospital where her mother was staying commenting that she did not know she could speak. For Helen this typified poor care since they did not even bother attempting to find out whether she could speak and led Helen to "fight her corner". Her husband was subsequently admitted to the same hospital so to maintain moral adequacy she was prepared again to fight his corner too. Helen's strategy to achieve this was complex and sophisticated and she positioned legal or policy frameworks to support her husband's care. The next excerpt provides a dialogue related to an interaction with a consultant and nurse specialist in a cancer hospital;

- | | |
|------------------------|--|
| 1 Helen: | and then of course |
| 2 | obviously with the |
| 3 | err |
| 4 | you'd have expect |
| 5 | errm |
| 6 | actually |
| 7 | the [name of cancer centre] to already have all sorts in place |
| 8 | because I said |
| 9 | when Greg was at the |
| 10 | errm |
| 11 | {name of cancer centre} |
| 12 | like at the {name of other hospital} |
| 13 | I had said |
| 14 | oh what |
| 15 | what |
| 16 | provision have you in place |
| 17 | for people with dementia |
| 18 | and all |
| 19 | you know |
| 20 | I'm saying dementia because |
| 21 | it [covers loads of things] |
| 22 Interviewer: | [of course it does, absolutely] |
| 23 Helen: | err |
| 24 | of course |
| 25 | and they said |
| 26 | err |

27 well
 28 and they were like this
 29 **Interviewer:** oh
 30 so you got no answer
 31 or they didn't tell you
 32 **Helen:** no
 33 they didn't know
 34 no
 35 no
 36 he said
 37 in fact {laughing}
 38 the surgeon said
 39 "I don't think we have
 40 have we"
 41 to the
 42 to the err
 43 specialist nurse
 44 when we were all in the room togeth-
 45 I asked it then
 46 you see
 47 **Interviewer:** yes
 48 **Helen:** what provision have you
 49 erm,
 50 well I don't think we.
 51 you know
 52 I think we should have had one
 53 a couple of years ago
 54 but
 55 you know
 56 I don't think it's happened
 57 **Interviewer:** right
 58 right
 59 they couldn't answer you
 60 **Helen:** so that was
 61 that was
 62 it fits
 63 and that's why
 64 I said about having access
 65 you know
 66 **Interviewer:** yep
 67 **Helen:** and everything like that
 68 because it didn't
 69 it wasn't the norm at that
 70 it wasn't the norm
 71 when I asked
 72 **Interviewer:** yes
 73 **Helen:** because she had to go and arrange that

74	with the
75	err
76	matron of the ward
77	sister
78	or whatever

Helen presents her expectations that some support should be available for people with dementia and conveys to the listener her strategy used in two separate hospital contexts. She used direct speech quotation to pose a question about provision and then clarifies and justifies the use of the general term “dementia” in the construction of her question to this unknown audience. I support her use of the word dementia and she then presents their hesitation with a further direct speech quotation of “well, err”. I interject, asking to confirm that no definitive answer was given and Helen responds indicating they did not know and she laughs at this point. She now lets the listener know the identity of the audience for her question, a surgeon and nurse specialist within a clinic room. After my continuer “yes” Helen re-presents the question and through direct speech quotation again positions the inadequate response from the surgeon related to an unfulfilled commitment years ago. This atrocity story highlights the foundering of a senior clinician when presented with a “commonsense” question of support for those people who are cognitively impaired. They should know or have provision and to maintain moral adequacy need to have processes in place. I confirm the inadequate response and then Helen evaluates this with reference to issues of accessibility for disabled people. This can seem to invoke a legal discourse surrounding reasonable adjustments: the coda of the story relates both to service provision for people with dementia and what should be the “norm” within inclusive care.

The predominately positive experience Helen presented may also be tied to the behaviour of Greg. Unlike the combatant relationships positioned by the other participants, Helen’s

identity as a carer was not challenged or contested by her husband. She commented that he was not somebody who goes wandering and contrasted this with another patient with a catheter who used to walk everywhere. Helen described her husband as very calm and she associated this with a good experience, contrasting this with “some poor people” who had to support people with behavioural challenges. Helen, at various points of the interview, summarized her approach to the events she portrayed, and this often involved a close monitoring of formalised care and an incisive intervention to challenge areas of concern. The following dialogue highlights this.

1 Helen:	yes
2	that's right
3	of course
4	so
5	I think
6	err
7	I'm glad I spoke out
8	I think as well
9	err
10	with speaking out
11	I think they thought
12	well
13	I can't get away with anything {laughing}
14	with this
15	with this lady {laughing}
16 Interviewer:	{laughing} oh I see
17	you're on the case
18	you're on the case
19 Helen:	yeah
20	that's right
21	I don't think they could get away with anything {laughing}
22	anyway
23	so
24	no
25	because you're
26	you're fighting that person's corner
27	you know
28 Interviewer:	yes
29 Helen:	you're speaking for them really
30	because

31 I remember
 32 as I say
 33 with my mum
 34 I just thought
 35 *oh my god* {laughing} (2.0)
 36 do you think she can't speak
 37 I just couldn't believe it
 38 **Interviewer:** yeah
 39 **Helen:** and with food
 40 and stuff like that
 41 which you know
 42 you obviously
 43 probably know
 44 happens a lot in hospitals
 45 they take the food
 46 leave it there
 47 and the poor person can't eat
 48 and then [take it away]
 49 **Interviewer:** [it's too far away]
 50 can't quite reach it
 51 **Helen:** yes that's right
 52 things like [that]
 53 **Interviewer:** [and someone] says
 54 you don't want your dinner
 55 I'll take it away
 56 **Helen:** yeah things like that
 57 yeah
 58 because I made sure
 59 when my mum was in
 60 I made sure I was there
 61 at mealtimes
 62 because of that
 63 **Interviewer:** yeah

Helen conveys her assessment of speaking out and presents this strategy as protecting her husband by making staff more vigilant and mindful in their care. She implies staff know they may be challenged and "can't get away with anything". Helen laughs and I reciprocate the laughter, indicating that she is in control of managing Greg's care. Helen reaffirms that staff could not compromise on care with her assertive positioning and this maintains both moral adequacy and her identity as a carer. This positioning is underpinned by a moral imperative

that Helen presents to the listener that “you’re fighting that person’s corner”. Helen further presents a justification for her position to the listener by referencing the advocacy work required for her mother, re-telling the comments made about her communication abilities by health staff. To avoid such atrocity stories requires advocacy work and after my acknowledgement token “yeah” Helen illustrates her point with another example associated with mealtimes. Helen acknowledges my nursing background by inviting me to reflect on hospital routine at mealtimes and presents a situation where food is left out of the reach of the patient. I take up this narrative and become a co-teller in a common atrocity story. I present a patient unable to stretch and reach their food and Helen with her agreement token of “yes, that’s right, things like that” affirm this elaboration of the story. I further expand on and develop the narrative by presenting the consequences of a patient being unable to reach, positioning the staff as assuming the patient has refused to eat. Helen again confirm by interpretation and in maintaining moral adequacy lets me know that, with her mother, she anticipated this and stayed at mealtimes.

Summary of participant issues (Helen)

Ward based staff appeared not to assess or address the person-centred needs of the participants relative.

Participant had to proactively manage the clinical situation to maintain person-centred care.

Participant had to navigate and use specialist services to maintain carer identity.

4.10 Alice's story

"Mr Smith promised we could bring him home."

Alice was in her 70s and had very recently lost her husband (Joe) who had penile cancer and Alzheimer's disease. He had died of pneumonia at home 5 days following an extended stay in a local hospital. Prior to this, he had had recent surgery to resect local metastatic spread at a specialist cancer centre. Alice had forewarned me that she would be emotionally fragile throughout the interview since it had been 4 weeks since Joe's death. She 'apologised' in advance; the subsequent interview was interspersed with crying and tears as Alice attempted to make sense of the events leading to the death of her husband. One of the functions of a story according to Frank (2010) is how it helps people individually and collectively to remember who they are and how these stories do the work of meaning.

"Stories are the ongoing work of enacting or performing memory" (Frank; 2010 p81) and with Alice this process was raw, fragmented and painful as the narrative(s) interweaved towards the finality of her loss, her life with Joe was now in the past; the present and future diminished in her bereavement. Her grief was palpable at interview and when I used the toilet the lifting and home adaptations of care were still present, a reminder of the intense home support that now would no longer be required. Alice felt that the health care staff were not sensitive to the needs of Joe and that this was evident from their exclusion of her within the treatment journey. The excerpt below highlights the issue.

1 Alice:	yeah and the same
2	when he went
3	err err
4	when we went down for this operation
5	err {upset}
6	I was with him
7	and I went down

8 I went with him
 9 and the nurse to,
 10 to, to the operating [theatre]
 11 **Interviewer:** [sure]
 12 **Alice:** but at err-
 13 at the, the doors
 14 they said
 15 I couldn't go in
 16 **Interviewer:** yeah
 17 **Alice:** but then
 18 when
 19 and i-I-I went in the front of {name of cancer centre}
 20 and the nurse come running after me
 21 she says will you come back
 22 err
 23 they want to ask Joe some questions
 24 **Interviewer:** oh
 25 and he doesn't know the answers
 26 so this was Joe going into the theatre
 27 **Interviewer:** yes, yeah
 28 **Alice:** and the nurse didn't know him {upset}
 29 and yo-you, err, errm,
 30 really they were only
 31 they were only questions that,
 32 that they ask a normal person
 33 **Interviewer:** yeah sure
 34 **Alice:** err you know how they
 35 it's [a]
 36 **Interviewer:** [it's a checklist]
 37 **Alice:** that's it it's a checklist
 38 it's a checklist
 39 and, and,
 40 being in- in a worried state
 41 and being an Alzheimer's patient
 42 he couldn't answer them
 43 **Interviewer:** sure, of course

Alice contextualises the story, going down to theatre with her husband and a nurse and after my acknowledgement token "sure" Alice identifies the trouble, a refusal for her to enter at the doors to the theatre. Unspecified actor(s) had denied her access but then Alice presents to the listener the drama of a nurse running after her. Her presence is now urgently required but this relates to questions Joe cannot answer in theatre, a clinical risk

management discourse rather than a person-centred approach to care. Alice further positions this coda of the story as about ‘knowing’ the person and specifies the nurse as a stranger asking generic questions suitable to people without cognitive impairment, ‘normal’ people. After my continuer “yeah, sure” Alice attempts to qualify the nature of the questions and I intervene, demonstrating my professional expertise and identifying this as a checklist. Alice confirms the accuracy of my description and then presents the emotional life of her husband within this context (he was worried) and reminds the audience that he was unable to answer due to dementia. Alice directs the audience to a set of questions generated exclusively for patients without cognitive impairment and presents the obvious conclusion and outcome in a patient with Alzheimer’s, “he couldn’t answer them”. This dialogue draws on how Alice maintains and accounts for caring, her carer identity challenged by exclusion from theatre. In contrast to Helen’s narrative and experience of theatre, Alice found navigating and engaging with the processes of formalised care more challenging. Throughout the interview Alice tried to present stories demonstrating the character and personality of her husband, and this was often juxtaposed to atrocity stories generated by non-personalised care driven by managerial drivers and clinical processes. This often meant Joe’s life was not fully narratable, and, as Frank (2010) asserts, “A life that is not fully narratable is vulnerable to devaluation” (p75).

Alice further positions the importance of a person-centred approach and explores the difficulties in maintaining her construction of Joe’s personality and character in the face of clinical challenges. The following dialogue presents behavioural issues that appeared out of character for Joe.

- 1 **Alice:** and you’re a n-
2 visitors are a nuisance so they’re never

3 not encouraged are they

4 **Interviewer:** no, no

5 **Alice:** at {name of local hospital} it was before 2 o'clock

6 so erm, and uh, uh,

7 there was one time in {name of cancer centre} where Joe

8 they brought, they brought,

9 Joe was not an aggressive person

10 he was a gentle person {upset}

11 **Interviewer:** mm

12 **Alice:** but {crying} he refused-

13 he refused

14 what, what the nurses wanted

15 this was in the evening

16 after we'd gone

17 **Interviewer:** yeah, sure.

18 **Alice:** and err they brought security to him? {crying}

19 which I found (2.0)

20 it wasn't, it wasn't because he was {high pitched} he wasn't,

21 he wasn't aggressive really?

22 but he just wouldn't do

23 what they wanted him to do

24 **Interviewer:** what did they want him to do

25 do you [know]?

26 **Alice:** [no], we never got

27 we never got to the bottom of it

28 **Interviewer:** right, right

29 **Alice:** no (2.0)

30 no

31 it was just

32 **Interviewer:** and what did the nurse say to then

33 did they say to you when

34 when [you]

35 **Alice:** [it was] afterwards

36 Errm

37 you see

38 he err,

39 after the operation

40 he had a

41 he had a catheter

42 **Interviewer:** yeah, sure

43 **Alice:** and err,

44 he found it very painful

45 **Interviewer:** mm

46 yeah

47 **Alice:** and all he wanted to do

48 was

49 to take this catheter out

50 err- errm
 51 and, and
 52 I think it was something to do with that?
 53 **Interviewer:** [oh, ok]
 54 **Alice:** [you know]
 55 that errm
 56 uhh
 57 I mean (3.0)
 58 Uhh
 59 If, if I was talking to him you could
 60 talk him into
 61 into a relaxed [state].
 62 **Interviewer:** [yeah] sure
 63 **Alice:** I use to say to him put your hands together
 64 and just sit back
 65 and think of something nice
 66 you know
 67 **Interviewer:** yeah
 68 **Alice:** I mean really
 69 err
 70 really Alzheimer's patients must, must be very difficult to cope with
 71 because err (1.0)
 72 unless, unless it's a loved one
 73 I don't think
 74 I don't think I could cope? {crying}
 75 with somebody else
 76 It must be difficult for them?

Alice had previously described the set visiting times and the busy nature of clinical practice and within this excerpt she designates herself as a visitor and immediately identifies this as being a nuisance. This assertion is then slightly tempered and redefined to "not encouraged" and Alice seeks further validation of this positioning from me. I affirm this with "no, no" and she then states that the event took place before visiting time. Alice presents somebody being brought to the ward but pre-empts this story by positioning Joe as a gentle person to the listener. This starting point and statement is presented as the overarching framework in which the teller wishes to interpret the subsequent story, and Alice's upset in

conveying this story stems from the contested reframing of her husband by nursing staff implicit in the event(s) that followed. Why would you bring security to the ward if Joe was a gentle person? Alice presents the conflict relating to her husband's refusal to comply with an unspecified request. This was positioned as occurring in her absence, and after my acknowledgement token "yeah, sure" Alice (who was crying) challenged the implication that he was aggressive and positioned an alternative explanation to the listener; he just did not want to comply with their request. Alice asks the audience if it would be reasonable to refer to security if a patient refused a request. I further ask Alice to specify the request Joe denied, she is unable to present the reason, and, on further probing related to the nurse's response, Alice tentatively suggested the pain associated with a catheter postoperatively as a possible trigger to the event. She presents the justification for such a suggestion by informing the listener that Joe was urgently wishing it to be removed. Following my acknowledgement token "oh, ok" Alice counters and minimises the potential conflict generated over an event that may involve post-operative catheter care by presenting the presence of herself as a mediating factor that would maintain her husband as a "gentle person" rather than "aggressive person". She would talk and relax him and Alice demonstrated to the listener how she would have achieved this, distracting him from focusing on the catheter. Alice ends the story with a more general acknowledgement of the challenges of supporting someone with dementia and singles out her identity as a carer. This can be seen as implicitly invoking the membership category of husband–wife (Sacks 1967). This identity and the moral adequacy required to meet Joe's needs is a tiring and demanding role and she positions it as particularly difficult outside of a close relationship.

One of the pivotal episodes the Alice returned to and repeated at separate parts of our interview was the mismatch that she felt was evident from how the family perceived Joe was doing and what health professionals felt about Joe's immediate prognosis. Alice and her family felt the weight was dropping off him due to an undiagnosed swallowing problem and wanted to take him home to die. This was a point of conflict with the consultant whom Alice presented as changing his mind as to the best way to support Joe. From an initial acceptance of the family's wishes, he then wanted to pursue artificial feeding and investigate why Joe's swallowing was affected. The dialogue below illustrates this point.

- 1 **Alice:** trying to get this mucus up
2 he, he was really, really poorly
3 (03) now it's going to have been the err,
4 err
5 the pneumonia that took over
6 and the doctor put on the death certificate
7 Broncho-pneumonia
8 and Alzheimer's
9 err
10 I don't know it
11 Mr Smith promised us that we could bring him home
12 **Interviewer:** mm
13 **Alice:** we, we said
14 we want to bring him home
15 without any artificial feeding at all
16 **Interviewer:** yes
17 **Alice:** err and this was
18 err
19 err (1.0) middle of the week
20 Wednesday
21 and then on Friday
22 err
23 when we thought he was coming home
24 they'd got
25 they'd got,
26 errm
27 a palliative care nurse
28 err
29 to come
30 and the sister said can you all come to this meeting

31 well we thought we were bringing Joe home
32 but then they threw at us
33 that they were going to do further investigations
34 err
35 and Dr Smith had backtracked on his agreement
36 that we could bring Joe home
37 without any artificial feeding
38 and if we didn't agree with that
39 he would involve the police
40 so it really, it really deteriorated.
41 **Interviewer:** so why, why, why was that
42 **Alice:** because uhh
43 **Interviewer:** why was conflict there
44 do you think?
45 **Alice:** (2.0) there was a conflict internally
46 I feel
47 **Interviewer:** right ok

Alice describes the physical process of why Joe was so ill and reiterates to the audience how ill he was, positioning the diagnosis of pneumonia to the subsequent medically certified reason for his death. She then presents to the listener the consultant's promise that he could be discharged home and after my continuer "mm" Alice reaffirms her family's wish of no artificial feeding. She then after some equivocation related to chronology reminds the audience that she was preparing for Joe's arrival home and then presents a meeting initiated by a palliative care nurse and sister with the family. Alice informs the audience of her 'commonsense' interpretation that this was a discharge planning meeting but then dramatically positions the sudden, unexpected reversal of this plan that was "thrown" at them with the introduction of unspecified further investigations. Alice reminds the listener of the consultant's backtracking and reaffirms to the audience what the broken promises were. She then frames this alternative plan as an authoritarian, unilateral decision underpinned by threats to involve the police. Alice summarises this communication

breakdown and I immediately take up this story and want to know why the police were positioned within this meeting. I further pursue this with a supplementary question about the conflict and Alice intimated that this might relate to internal medical or legal discussions that she was not privy to. Alice discussed further the issues surrounding Joe's swallowing and indicated that the medical team felt it was not connected to either the pneumonia or dementia and therefore warranted further investigation and nutritional support. This can be conceptualised in what Mattingley (2010) describes as a biomedical genre of "healing as a machine repair". Although Alice and her family could see a dramatic deterioration in Joe there was no clear clinical certainty that this was not reversible. This clinical drama was a puzzle to be solved and the family were obstacles to this endeavour. In this "science detective story" the clinical picture must be constructed and addressed and, as Mattingley (2010) suggests

"Canonical biomedical genres carry moral imperatives. It is not simply that one has the technical capacity to repair a broken body/machine or attack a virulent cancer. One has the moral imperative to do so." (P212)

Alice presents the medical team as contesting her identity as a carer and preventing her accomplishing care. This was particularly apparent since Alice could not receive funding under continuing care whilst her husband was still having investigations. This access to funds required district nurse support and was eventually obtained. Alice's moral adequacy was threatened since Joe spent only five days at home until his death, with limited resources to support a "good death".

Alice's narrative(s) were also punctuated with stories exposing often thoughtless behaviours and she often positioned these as "small things" but significant in the evaluation of

formalised healthcare's ability to respond adequately to people living with dementia. An excerpt below highlights one such incident within our interview.

- 1 **Alice:** yes in the same ward but
2 in err
3 in err
4 he wasn't in a side ward
5 and he'd been nil by mouth
6 he was nil by mouth
7 err because of his complaint
8 and what they were investigating
9 and then
10 eventually
11 when they put the tube in it
12 he was still nil by mouth
13 but every day the drinks trolley
14 came
15 **Interviewer:** mm
16 **Alice:** and because his bed is first
17 the drinks trolley stopped outside his bed
18 and they gave drinks to everybody
19 but he didn't get one
20 and then when the food trolley came in
21 the food trolley was plonked
22 at the bottom of his bed
23 and everybody got a meal
24 and Joe didn't get one
25 I-I know it's no good
26 but if they just put the curtains round
27 or just isolated him in a way when
28 **Interviewer:** yeah
29 **Alice:** I-I know it's little things
30 and they're running like

Alice presents the trouble and prefaces the story with her husband's location and the clinical necessity for being nil by mouth. She positions the investigations, the feeding tube

and nil by mouth within the context of the arrival of a drinks trolley. After my continuer “mm” she further locates the proximity of Joe’s bed to the drinks trolley and highlights his exclusion from this social process. She then expands the exclusion to include food and presents a similar location of the food trolley to her husband. Alice positions herself as someone who is not naive as to the clinical reasons for this exclusion but presents to the listener an answer to this “atrocious” story and asks the audience a question: why cannot someone think about this scenario from the perspective of someone with cognitive impairment? I acknowledge this and then Alice presents this as a “little thing” and immediately acknowledges staff activity as a justification to the listener of why these “small” acts are neglected. These acts of thoughtlessness and lack of effective communication were a common feature throughout the narratives that Alice conveyed.

Summary of participant issues (Alice)

There were significant issues with health professionals involving the participant in care decisions and keeping them informed of treatment planning.

There were challenges with assessing mental capacity and conflict between health professional and relative which made navigating the cancer treatment journey safely potentially problematic.

Ward based staff appeared not to assess or address the person-centred needs of the participants relative.

There were issues with stigma and dementia.

4.11 Summary of the chapter

This chapter has examined the narrative co-constructions participants engaged with in interpreting their experiences. These data were examined through a case study approach to maintain a holistic approach to narrative exploration, and any commonalities between cases have been further explored within the discussion chapter. Capturing the interaction between teller and listener is an integral part of a performative narrative approach and is therefore an important element in choices made in regard to transcription conventions. Attention to turn taking within an interview interaction is also an important focus, and how subsequent positioning is achieved through this discourse creates the contextual meaning. It is through the description of this interaction that issues of reflexivity are addressed. I have framed some of the narrative(s) through the lens of atrocity stories (Stimson and Webb; 1975) since most participants appeared to position their stories in a way that could apply to this interpretative schema. Within these data there is evidence of the challenges to participants in navigating a path through complex cancer treatments in supporting their relative. A cancer diagnosis often requires multiple treatment visits to an oncology centre and this can be challenging for carers. They find that they need to co-ordinate and manage both health professionals and their relative in terms of getting access to appropriate services and support. This process can be particularly challenging in the presence of a cognitive impairment that often demands effective communication within different agencies. Carers frequently experienced multiple challenges include dealing with the stigma which is characteristic of the dementia experience and the added complexity of negotiating this within a cancer care context.

Chapter 5

Discussion

5.1 Introduction

This chapter will unpack and critically explore some of the narratives underpinning the interactions with the participants and the cultural framing implicit (and at times explicit) within the discourses of interview conversation. It will examine the stigma associated with dementia and the implications this has in the context of cancer care. It will examine the issues related to personhood and dementia and how these narrative genres shape our cultural lives and (de)limit the stories we can tell about ourselves. It will examine resistance and narrative repair and how participants positioned their relatives to try to protect identity and personhood. It will also focus on carer identity and how this can be contested by both the participant's own relative with dementia (and cancer) and healthcare professionals working in oncology. The chapter will then focus on how narrative approaches to care can, perhaps, offer a more authentic and person-centred response to the complexities of carer need from health professionals. Finally it will examine the implications in relation to the wider evidence.

5.2 Themes related to data

The underlying narrative themes will be described throughout this chapter and how they were generated from the participants' experiences will be articulated. In particular, issues of dementia and selfhood and the biomedical narratives that frame experience will be explored. Issues of decision-making and narrative repair were also significant and within the data generated Helen's experience was positive and appears in contrast to the other

participants. This “deviant case” highlights the more positive outcomes if participants have the ability and resourcefulness to effectively navigate the healthcare system. Helen proactively managed healthcare encounters and narratively read the situations and intervened to support her husband. Therefore, she described managing his nutritional requirements, contacting the dementia nurse specialist and challenged medical staff when she perceived care was compromised. Helen identified and utilised supportive staff to maintain a person centred approach for her husband. This proactive management of the potential challenges of someone with cognitive impairment was acknowledged by Helen as the most effective way to maintain carer identity. This was also facilitated by her husband’s behaviour and Helen positioned him as not a “problem” and very easy going and non-conflictual. Within the care triad of health professional, carer and patient there was uniform consensus managed by Helen. This is in stark contrast to other participants, for example, Lauren, Lynne and Alan, Susan and Betty. Their ability to manage or navigate healthcare was compromised either due to multiple care commitments, a lack of specialist mental health support or conflictual relationships with their relative with dementia. Some of the other issues that appeared to be ethically more straightforward for Helen to navigate was in relation to decision-making. Her husband had a curative cancer and the outcome was more unambiguous than the relatives of the other participants. For example, Susan or Lauren had to try and both convey complex treatment therapies to their relatives and also attempt to examine wider issues of quality of life in the presence of advance disease. This more complex decision-making was challenging to negotiate with both health professionals and their relatives.

5.3 Dementia and selfhood: “the person in jeopardy”

The participants within this study were concerned with maintaining the personal integrity of the person they were supporting – Lauren, for example, in positioning her mother’s academic achievements to counter the stigma she felt in her interactions with medical staff. This positioning was prevalent throughout Lauren’s dialogue and she described other events in which her father would attempt to take control of clinic visits and challenge some of the questions directed at factual recall of his medical history. Lauren positions her father as being unable to remember the chronology of his medical history but he would challenge the consultant to read the medical notes that already contained that information. In a similar vain, Jane attempted to maintain the personal integrity of her father in a clinic situation by not openly contradicting him when he presented a situation that Jane contested. Within the context of dementia and the identity of self, the construction of selfhood remains relational and posited publicly by our engagement with discourses with others such as, for example, storytelling. The carers within this study attempted to position the care recipient in ways that maintained identity either through supporting membership categories (Sacks 1992, Baker 2004) in situations where the dementia could threaten and contest these relationships. The extent to which the carers violated the social ‘rules’ and intervened within medical and formalised social care encounters was a moral issue which required open acknowledgement throughout the interviews I conducted. Without the engagement and co-operation of others within social contexts there is no meaningful construction of ‘selfhood’. Positioning and framing people with early stage of dementia can, as Sabat & Harre (1992) indicate, “place a person in a certain amount of jeopardy” (p454). This jeopardy can be identified in two major limitations placed on narrative agency of people

with dementia (Baldwin 2009): firstly, the narrowly defined nature of linguistic or narrative convention(s) and secondly the limited opportunities for narrativity with people living with dementia. As Bruner (2002) has commented:

“it is through narrative that we create and re-create selfhood ... (i)f we lacked the capacity to make stories about ourselves, there would be no such thing as selfhood” (pp85-6).

These constraints identified are extrinsic and constructed rather than an integral part of a dementia diagnosis and highlight the (de)limiting narrativity that is constructed and imposed upon people living with dementia. Lauren, Lynne and Alan, Jane and Helen all position instances of positive communication by health professionals based on narrative inclusion of their care recipient. Narratology involves linguistic moves that are ongoing and construct meanings (Thornton 2006), and Frank (2010) warns us that “a life that is not fully narratable is vulnerable to devaluation, silences can be equally injurious. Stories enact realities: they bring into being what was not there before, a life is effectively invisible until a story makes that life narratable” (p75). The carers within this study can be seen to attempt to maintain personal identity by supporting narrative agency and benchmarking this both as a marker of the quality of care and as an ethical imperative.

Baldwin (2009) calls for a “reconceptualising” of the issue(s) in order to maintain inclusivity within the narrative enterprise. The boundaries of linguistic conventions need addressing since “to express oneself narratively requires a degree of conformity to narrative rules or habits or customs” (p29). Memory loss, disorientation and a limited expressive language may render impossible a narrative engagement with the other. Betty, Alice and other participants’ positioning of atrocity stories often demonstrates a lack of narrative engagement, and the subsequent silencing of these narratives led to compromises in care.

When health professionals did not engage in the wider narratives of patients' lives and involve carers in bridging the potential biographical disruption of someone living with dementia, events such as Lynne's brother not having a shower for two weeks or Betty's partner's inappropriate hospital discharge can occur.

Butler (2009) discusses what it is that determines a life as recognisable. Persons are situated in a production and (re)construction of social norms and "where a person is situated on the spectrum with respect to his or her alignment with these terms will determine if the person's life is grievable". Butler (2009) suggests that all lives, as social subjects and practices, are born precarious and thus we are intricately involved and dependent upon others independently of whether we know them or not. Our lives, as such, are therefore always precarious and in the gift of others. She poses the question: why are some human lives worthy of protection? This issue, although initially examined in relation to war by Butler, has relevance to dementia and the attempt of carers to position their care recipients as grievable appears a key concern. As Butler comments, "only under conditions in which the loss would matter does the value of life appear. Thus, grievability is a presumption for the life that matters" (p14). If a person living with advanced dementia has lost the capacity or desire for an identity then others need to sustain and nurture such an identity as an ethical imperative. This sustaining was evident throughout my dialogue with carers, and maintaining moral adequacy was often situated in navigating and positioning the primacy of care recipient identity.

We also need to examine the meta-narratives of dementia that can define identity, for example people living with dementia as 'empty shells', or just 'waiting to die' (Gorp & Vercruysse 2012). Johnstone (2013) further examines metaphors that are operationalised in

relation to euthanasia and Alzheimer's disease and questions the context in which the latter is seen in metaphoric terms as an epidemic, a battle and a predatory thief metaphor in which the disease robs someone of their personhood. These construction(s) can limit opportunities of people living with dementia to contribute or be recognised as contributing to the narrative constructions of others. In two poems below, Peterson (2009) communicates the pain and loss experienced with his mother. The remnants of her narrative life are scattered in her belongings, creating the remembering of past events. The palpable grief is situated in absence, in the ambiance generated from someone to something else, narrative foreclosure has ended life before death. As Kaufman (2006) comments:

"In its various stages, early, moderate, advanced, severe and end stage, dementia is a condition both of death-in-life and of life-in-death. This ambiguity becomes more profound as the disease progresses and it lies at the heart of the anguish about what to do. This ambiguity is what makes dementia so compelling for families, so unnerving in the context of the cultural importance of memory, control and reason and so unsettling to the existing order of things" (p23).

In the second poem Pies (2009) highlights and questions meaning beyond biomedical narratives of dementia. The biological description of the disease process, of the plaques and tangles, provides little narrative meaning to the ongoing work of carers in redefining a 'meaningful' life for their care recipient. It requires ongoing counter-stories and identity work to maintain moral agency and prevent narrative foreclosure.

Finding Mother

Scott Peterson

I found my mother
The other day, hiding
Inside a desk drawer,
way in the back, behind
an old telephone book, next
to some loose change

She was inside
an old pocketbook,
the one she hasn't used
in ten years, since
she began to wander, and
we took her keys away.

Just flip it open and
you'll see her, plain as day.
Pictures of sons and
husband, her two grandchildren,
neatly arrayed on top.
Then insurance and credit cards,
each tucked away in their own
pockets,.
The driver's license, of course,
perfectly placed for easy display.
An old grocery list, some
appointment cards, all
square corners and right angles.

There she is,
all of her,
before she disappeared
and became something else.

p44

Figure 5.2: Finding Mother

From The Alzheimer's Sonnets

Ronald Pies

Sonnet for a Missing Singer

The doctors say some pinkish
sludge
is what does you in. gods of
amyloid
and twisted strands that just
won't budge
from the brain. Pretty soon, a
void
of neurons hangs like some old
moth-eaten sweater, where once
a solid weave of bold
thought reigned. Yet the soul
hunts
for clues among the mind's gray
runes,
and now and then finds some
Rosetta
Stone of memory-an old Sinatra
tune
that brings back spirit, if not the
letter.
Love, these cells that wink out
one by one
are not the song of all that we've
become.

(p 83)

Figure 5.3: The Alzheimer's Sonnets

In moving from identity to cognition, the defining characteristic of selfhood that appears tied to cognition requires challenging. Persons as situated, embodied agents can act with

purpose without explicit awareness or consciousness (Aquilina & Hughes 2006). Purposive relationships can develop and are often situated in an embedded context. Katz (2013) examines the historical context of dementia and personhood, examining the medieval constructions of memory and the potential support of a more embodied approach that this perspective offers. Firstly, *“memory is an act of agency and imagination, not simply a passive and cognitive process of input and output”* (P311). Secondly, memory is a force that intersects individuals, environmental and worldly forces beyond and between individuals, across communal spaces and collective activities. Thirdly, memory can be expressed on and through the body, *“our great symbolic resource for embedding and emplotting our lives even when our minds might fail us”* (P311). Fourthly, memory loss is not necessarily a disease but a contingent condition of growing older. The cognitive status of older people is part of the cognitive status of people at all ages because memory is adaptable at all ages. *“Reducing people to their brains and isolating them as sick and marginal in the name of cognitive care harms memory, which is continual even when forgetful”* (p311). Finally, memory is emotional as well as cerebral, and to separate the two means failing to understand memory as an ‘act’ as well as a ‘science’. The pathologising of memory within a biomedical framework reduces memory problems to individual cognitive dysfunction rather than seeing the diverse context and form in which memory is transmitted and employed. This focus on issues of embodiment is also explored by Kontos (2005) who, like Aquilina & Hughes (2006), challenges the maintenance of selfhood through primarily socio-interactive engagement. It becomes more than just the ethical response of the other in relation to advanced dementia, as Radden & Fordge (2006) suggest, but rather a full acknowledgement of humans as embodied beings. There remains a cultural ‘script’ embedded in complex social

relationships. The implication of this is that individuals bring to social interaction, as Kontos (2005) asserts:

“by virtue of their embodied nature a degree of intentionality and creativity that is ignored in person-centred care as it is currently practised” (P557).

Smith (2009) uses Bourdieu’s concept of habitus in relation to dementia. He defines habitus as a “system of personal dispositions that are constituted by lasting, acquired schemes of perception, thought and actions” (p38) and highlights the failure of habitus for those living with dementia. Habitus operates and is mediated within the cultural field which becomes unintelligible to others as the dementia progresses. Smith (2009) comments that

“the lack of intelligible habitus puts those with dementia at risk of being displaced from the cultural fields to which they belong by formal and family caregivers alike” (p40).

There is a loss of a public form of the self, and in a culturally highly regulated society any failure of habitus becomes a significant liability for individuals with dementia. Frank (2010) further explores narrative habitus and characterises this as situated in a repertoire of stories that must be culturally recognisable to both the person and the community in which it is located. It also facilitates a tacit knowledge of embodied practice in which the repertoire of stories are operationalised and understood. With narrative habitus this competence enables communities to recognise and predict the response to a particular story format. It also disposes a person’s task in stories and (de)limits the future stories someone will be receptive to. Which stories a person responds and is receptive to out of all available stories provides their narrative habitus, and as Frank (2010) reminds us “most human responses to stories are tacit, embodied and predisposed” (p54). A person’s predisposition is

characterised by how stories should develop, fit and make sense. This functions in the recognition of stories and how they are taken up, stored and located in one's inner library of accumulative stories. Betty, for example, positions a series of atrocity stories (Stimson and Webb 1975) and, through this, characterises how the stories should be received and interpreted. One of the noted linguistic strategies used by participants in Labov and Waletzky's (1967) research is self-aggrandisement which is designed to place the narrator in the most favourable possible light. It can position the narrator in the role of hero or, as in the case of Betty, as a victim, in an account that has the overall effect of exaggerating and therefore manipulating what actually happened. Betty presents a situation whereby her positioning of a separation between mental and physical health leads to dramatic consequences for her partner. Her dialogue is repetitive and in her telling the utility of her narrative as an enactment of resistance becomes apparent. She asks the audience how these atrocity stories could happen and gives an account of how she maintained moral adequacy in the presence of such neglect. The stories and narratives generated by my participants are not the final word, and the co-construction of the dialogue means there is a spontaneity and at times challenge to the narrative presentation. Frank (2010) reminds us that:

"situating any one story within those multiple stories does not finalise participants either singly or as a collective. It is not more than any participant could say but is more than any participant is currently located to say" (p102).

Issues of ageism can also exacerbate the challenges for people living with dementia and their carers. The "double whammy" of stigma related to mental illness and age discrimination as well (Godfrey et al 2005, Scodellaro & Pin, 2013). Old age stereotypes are

usually negative, focusing on incapacity and helplessness. Hakan (2012) used social identity theory to explore the construction of older people as “the other”. A temporal construction of old age and older people allows non-old people to see older people as substantially different to themselves. Ageism has been described by Levin and Levin (1980) as rooted in the tendency to construct old age as the primary cause of older people’s problems. There have been attempts to present a different narrative to counter this prevailing cultural frame. It is a discourse in which the ‘new’ old are now the active and assertive, living life to the full. There is no dependence or health concerns within this narrative of self-fulfilment and goal-orientated living but this narrative silences the frail and unwell, stigmatizing dependence and positioning burden as a consequence of care and gratefulness as the only morally appropriate response. The carers within this study are unable to enter the positive narratives of older age characterised by the third age within the context of dementia. Old age is typically associated with an awareness of finality, the limited future narrative possibilities (Carstensen 2006). This awareness was particularly acute for carers as they grappled with irreversible cognitive impairment within the context of a cancer diagnosis.

5.4 Biomedical narratives

The framing of dementia within a biomedical context can present wider challenges for carers, and Chaufan et al (2012) note the ambiguity associated with a medicalized discourse on cure and care. They highlight the framing of dementia as requiring expert intervention(s) that often exclude carers, with even ‘care’ conceived as a series of treatment or behavioural management interventions that fail to include the narrative(s) of both the carer and care recipient. This framing can be particularly problematic with the therapeutic nihilism associated with dementia and the tendency of biomedical approaches to focus on the

individual to the exclusion of the wider social networks and mediators to which we belong.

Radden & Fordge (2006) challenge this ideology of individualism that can isolate and define the subject in a way that compounds social isolation:

“Consistency suggests that what was begun by others should be continued by them. And this point would not so readily be lost from sight were the distorting ideology of individualism which casts each person the master of their fate and captain of their soul to be replaced with more realistic, collectivist assumptions-as it surely should be.” (p82)

People live in networks rather than isolated from the social context of life; however, contemporary healthcare appears concerned with refocusing to an individualistic, disease-orientated approach that can be seen to negate carer involvement. Bartlett and O’Connor (2007) contest the boundary of personhood in that they challenge the extent to which this conceptualisation promotes agency: if it is endowed upon someone with dementia then it is a category assigned, the person becomes a passive recipient dependent on external validation. It is bestowed by the cognitively intact and minimises the social agency of people living with dementia.

Notions of personhood would seem to need further exploration, and Nolan et al (2004) use the framework developed by Mulrooney (1997) in order to move away from concepts of personhood based on an understanding of autonomy as independence and individualism. The ‘Senses Framework’ (Nolan et al 2001, 2002) attempts to present and capture a more multi-faceted view of caring relationships incorporating both interpersonal processes and intra-personal experiences of giving and receiving care. All parties involved should experience relationships that promote a sense of security, belonging, continuity, purpose, achievement and significance. For caregivers, respect for personhood is associated with

both a value for interdependence and investment in caregiving as a choice. It would seem important to acknowledge the 'multiple voices' that exist within caregiving relationships and developing strategies in which carers, health professionals and people living with multiple co-morbidities can be meaningfully involved within different complex environments. Dementia care is often provided within these dementia care triads, and the interplay of conversational and social practices undertaken by dementia care triad members can position them in certain ways (Adams & Gardiner 2005). "Negotiating the balance" and working through interactions that may advocate for a carer's relative or antagonise their position in terms of decision-making and choice was a key issue for the participants (Quinn et al 2012).

Jane, for example, described the challenges of receiving comprehensive information regarding her mother's health whilst she was in hospital since staff kept telling her to speak to her father (even though they were aware that he also had dementia). This was in spite of her having power of attorney. Betty positioned herself as unable to get a realistic assessment of her partner's condition and appeared excluded from the discharge process. Mattingley (2010) presents a context underlining this apparent isolationist approach to patient care and she asserts there are three genres that often present in healing narrative emplotment(s) associated with biomedicine. They are: healing as sleuthing, healing as battling disease and healing as repairing broken machine-bodies. They provide what Mattingley (2010) refers to as "an authorized action framework" (p54) in order to interpret both the narrative ground and expectations of how these healing dramas should unfold. In the enactment of this narrative structure the constituted discourses that are generated silence other "facts" or voices that do not coherently fulfil the narrative construct

presented. In the first genre the sleuthing is constructed as a medical mystery to be solved and this can usually be enacted without recourse to family or friends or even the patients themselves since it can be solely diseased-focused. In the second cultural genre, healing as battling disease, the clinician and invading disease take centre stage. The body becomes the site of “battle” with clinicians fighting this disease process and this genre is typically characterised by military metaphors, such as the ‘war on cancer’ (see Sontag 1978). The final cultural genre, healing as machine repair, is taken from Davis-Floyd and St. John’s (1998) interpretation of the body as a machine that can therefore be ‘fixable’. It provides a mechanical metaphoric framework in which the clinician becomes an advanced mechanic able to remove, replace or adapt parts of the body that may have broken down. In all these three cultural genres the family or carers can be sidelined as superfluous to the healing process. They can provide at best socio-medical information to inform a clinical approach and, at worst, untrustworthy historians whose input may be perceived as unreliable, irrelevant and a hindrance to the discourses of medical care.

5.5 Dementia and ethics on the borderlands: redefining hope within cancerland

In relation to cancer care, Frank (1995) developed three dominant narratives or genres based on his own experience of cancer and in dialogue with others who had been through the diagnostic and treatment journey. The restitution narrative positions a discourse that asserts: “Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again”. It represents a narrative in which the expectation is of recovery. It may be associated with a transient period of illness and incapacity (associated with the disease and treatment) but restitution remains the primary goal and outcome. Most clinical encounters represent this encounter and this is (re-)presented in many cultural frames associated with cancer. Positive

thinking after a cancer diagnosis is a popular narrative construct with the associated requirement of battling or being courageous in the face of the diagnosis, treatment and then recovery. This is probably best characterised by what Frank (1995) describes as the Quest narrative in which quest stories purposively face the suffering, accepting the illness, and positively use this experience as a means to grow as a person. Perusek (2012) offers a moving account of his brother's struggle with lung cancer and highlights the cultural frames that become what he describes as anti-resources in attempting to interpret experience. He argues that the requirement to take up and utilise the war-like metaphors may reflect that dying in:

“the wake of battle confers social approval on the deceased by suggesting a culturally mandated positive attitude had been maintained to the end, full of determination, fight and fighting spirit and that doing battle sustains the political illusion that much has been done and much can be done in the fight (personal and societal) against the disease” (p497).

Ehrenrich (2001, 2009) highlights the discourses in 'Cancerland' and demonstrates that the power of positive thinking is saturated throughout popular media. This silences other stories and reduces the available narratives or, as Frank (2010) would suggest, “companion” stories that could be taken up and positioned by people with cancer. Bell (2012) refers to the “teachable moment” within cancer survivorship and argues that a feature of the health literature is the positioning of life events, of transitions as a vehicle to moderate behaviour. She highlights the elements required for this process as increasing perceptions of personal risk associated with a significant emotional response and a redefining of personal identity or social role. The perceived shock of a cancer diagnosis can be constructed as a positive avenue for self-management and lifestyle modification, the remaking of self. It can be a

quest for what Bell describes as post-traumatic growth. Those who do not acquiesce to this narrative are positioned as “pathological, deemed to be ‘marked’ by fatalistic attitudes and misconceptions that need to be dispelled by clinicians” (p587). The cultural frames of trauma associated with cancer calls people to act, it is not neutral and compels a person to demonstrate an ethical and moral position. Are you stuck in a post-traumatic barren wilderness unable to manage the available cultural frames to move on and overcome these barriers or are you someone who can consolidate your experiences and move into communities of survivorship? Segal (2012) examines narration in breast cancer and reflects on her own personal experience as having a “distinctively anti-pink tinge”. She describes the email response she received after publishing an article in a local paper challenging some of the narrative constructions in breast cancer and identified six themes in these responses. The first was the burden that was perceived in requiring to be positive and “pink-minded”. The second is the misrepresentation of cancer when it is portrayed as enriching, heroic experience (Stacy; 1997 was particularly concerned at the damage of this anti-resource). The acknowledgement of the day-to-day struggle was more supportive than reference to strength of character and other associated attitudes, and Segal (2012) points out that “to congratulate the person living with cancer for strength and ability is also to assign responsibility for health and illness to that person” (p301). The last two themes Segal identified were that the giving of unrealistic reassurances by friends and family was counter-productive and increased stress and burden and that particular kinds of cultural frames (de)limited the space for alternative companion stories.

The final narrative that Frank (1995) identified was the Chaos narrative, which is difficult to define because there is no story, only suffering. It is this narrative that Frank suggests is

difficult and challenging for health professionals because it troubles both the restitution and quest narratives that ground many of the available cultural frames within contemporary western healthcare. This chaos narrative can be seen with the context of the carers' stories and articulated through the atrocity stories presented. It can be seen as a narrative frame that represents the journey of most of the care recipients within this study and the carers' dialogue attempts to position the experience as such. The borderlands of dementia and cancer exacerbated the limited availability of companion stories, of cultural frames that could be a resource in supporting the person living with cancer and dementia. I have defined "borderlands" in a similar way as Hinton et al (2006) in which *"clinical encounters in primary care have the potential for intimacy and supportive intervention as well as conflict, misunderstanding and unnecessary or even dehumanizing medicalisation"* (p44). The borderlands are situated in encounters where two or more cultures edge each other, they retain the properties of fluidity, identity making and potential marginalisation as cultural (mis)recognition can silence alternative narrative resources (Mattingley? 2010). The ambiguous and contradictory nature of multiple cultural frames needs to be navigated within clinical encounters in order to prevent foreclosure of positive companion stories that support the making of self.

The current cultural frames of restitution and quest within cancer care cannot find traction in dementia care. The remaking of self, articulated by Bell (2012), appears inappropriate within the context of dementia. There is no "teachable" moment(s) because of the foreclosure of a narrative future. Bell (2012) asserts;

"contemporary oncological discourses on cancer survivorship appear to be premised on this neoliberal logic of privatised risk management, whereby the 'good' subject/citizen is

expected to take responsibility to manage his or her risks of cancer recurrence to alleviate the financial burden otherwise imposed upon the tertiary healthcare system” (591).

However, this cultural ‘calling’ exempts those whose personal agency is compromised. King (2006) has referred to these cultural drivers in relation to breast cancer in which the empowered patient who can be signified as a survivor, activist and expert are embedded within the cancer establishment discourse. The battling metaphors, however, do not apply and create ambiguity and a silencing of cultural frames for both the person with cancer and dementia and their carers. There appears no remaking of self that applies to dementia.

When Susan tentatively explored whether her father should have had cancer treatment she was contemplating the foreclosure of his narrative future. Would it have been better for him to die more quickly from cancer than experience the slower cognitive deterioration that dementia brings? Lauren again was concerned about any major surgery her father might be offered for bladder cancer and was mindful of his quality of life with a co-existing dementia. Freeman (2011) describes his struggle with his mother’s dementia and has concluded that *“narrative foreclosure may have less to do with the reality of imminent death than with the conviction that it is simply too late to live meaningfully”* (pp12-13). He makes the point that in wider societal engagement the development of narrative function is foreclosed in people living and dying with dementia. In the treatment of Betty’s partner by healthcare professionals in hospital and of Linda’s brother and Lauren’s mum and Alice’s husband there appears a silencing of narrative and, as Frank (2010) asserts, *“a life that is not fully narratable is vulnerable to devaluation. Silences can be equally injurious”* (p75). The participants attempted to utilise stories as enactments of resistance or what Nelson (2001) describes as counter-stories to repair damaged identity. In the moving account of Jane’s

struggle to maintain moral adequacy (in the light of her parents' deterioration) any counter-story had limited cultural legitimacy, the silencing of alternative frames left a hopeless vacuum exacerbating her isolation as a carer. A number of the respondents intimated this isolation, particularly with the limited formalised care encounters that occurred. This isolation resonated with Perusek's (2012) description of a recurrent narrative often presented to him in supporting his brother with lung cancer: "I just can't imagine what you're going through". This is a particularly challenging narrative as he notes:

"It marginalizes the person whose experience it suddenly frames by locating that person's experience not only beyond the ordinary scope of human experience, all of which would be quite bad enough but also all the way beyond the pale, not merely even of understanding but, past that, of human imagination itself. As if the constant companionship of cancer, the reduction of life to ritual poisoning by chemotherapy and radiation and the existential weight of it all isn't marginalizing enough, this speech convention and cultural frame totalizes the marginalizing of cancer victims and their loved ones by denying the universal character of illness, dying and death, together with the existential anguish that is its universality unites everyone, everywhere" (p488).

This marginalization and subsequent isolation is further characterised within dementia cultural frames to question even the point of cancer treatment. Carers have to give a moral account of themselves in supporting active treatment: since restitution is not an option, why bother? It becomes not just beyond human imagination but a case of the absence of human imagination. The popular cultural frames of "the living dead" (Aquilina and Hughes 2006) and "zombies" (Behuniak 2011) that can characterise perceptions of dementia point to what Agamben (1998) refers to as a space without rights located between life and death – an

empty existential space that situates the primacy of embodiment when the language of personhood fades in the foreclosing of personal narrative. There are no cultural hooks to prevent a sliding through the gaps of narrative legitimacy and into a void without a counter-story. Without this effective counter-story identities are marginalised and silences are distilled within narrative foreclosure. In a poem by Zeeb (2009) she describes her relationship with her mother (living with dementia) when language is lost:

Sarcophagus

Side by side
hands entwined
my mother and I
recline on
her narrow bed
keep company
with the spirits
emanating
from photographs
of ancestors
Japanese prints
beloved objects
from her past
lives
Eyes closed
we breathe in unison
suspended
for a time
I forget
her forgetting
Her fingers
in mine
slender
long
familiar

(p150)

Figure 5.4: Sarcophagus

Her relationship becomes a narrative reality in the embodied experience that she has with her mother. Her remembering is invoked in the other. In this sense it may be better to think of this as an activation of 'remembering' rather than 'memory' as something in memory or retrieving something from memory (Chafe 1994). In terms of dementia, this view may counter the perception of memory as a place, which metaphorically can then be 'removed', or 'eroded' by a disease process such as dementia. If personhood were perhaps viewed as an invocation of remembering then narrative framing such as dementia robbing the individual of their personhood would become nonsensical. When Lauren describes her mother's achievements in the face of her characterisation as a "little demented lady" by a consultant, and when Alice conveys the kind, gentle nature of her husband in response to his behaviour on the ward, they are both invoking remembering and attempting to prevent narrative foreclosure. They are the ones who attempt to forge connections and link past to present. The pressure to 'create' oneself is a pressure of late modern identity construction, and as de Lange (2011) comments:

"The better that story, the more they are somebody and the more their lives make sense. Narrative self-creation as the only means remaining for identity construction is a myth that distorts reality. There are other ways for late-modern individuals to construct their personal and social identity without much reflexive and or narrative labour" (p56).

Katz (2013), describes a medieval perspective of embodiment, and this may present a more helpful construction than the post-Cartesian mind/body split in supporting positive cultural framing for carers and people with dementia. If personhood is defined and located in the mind, biomedical narratives can exacerbate and perpetuate a reductionist interpretation of personhood that positions narrative foreclosure as an inevitable consequence of advancing

dementia. Carers have to negotiate and function in the shadows and borders of narrative possibilities, advocating and positioning their care recipient in a positive cultural light. This cultural framing is explicit and implicit within the dialogue with carers, and opening up spaces and counter-narratives within the schema of atrocity stories was an unfolding, continuing enterprise. Ehlers's (2014) position of vulnerability is of interest here and she asserts that this is more productively understood as a relational ontology. So beyond the commonly acknowledged physical vulnerability that a cancer (and dementia) diagnosis brings,

"a space is opened up to grapple with the relations between flesh and self and between bodies and knowledge. Thinking of vulnerability as a relational ontology means looking at the arranged separations of mind/body, self/flesh, organic/inorganic, order/disorder, inside/outside and life/death that fail or collapse in the face of illness" (p128).

Our narrative lives are often presented or perceived as coherent, unique and unified but, as Butler (2005) reminds us, the "I" has no story of its own external to our relational lives and a set of norms that govern such as life. Illness and particularly life-limiting conditions challenge the artificial constructions we generate from the cultural framing available to us. It highlights and positions the vulnerability carers express in maintaining and supporting care recipient identity and the moral adequacy required to facilitate this process. The ethical imperative of remembering the old self of the care recipient is significant since recalling biographical fragments signifies both their moral agency and fully developed interacting self that historically existed (Karner & Bobbitt-Zeher 2006).

5.6 Maintaining moral adequacy: counter-stories and narrative repair

Nelson (2001) highlights the damaged identities that cultural framing can generate and examines how narrative repair can be positioned to generate counter-stories to maintain the moral integrity of the oppressed group. She interprets identity as the person's self-conception of how others view them and the understanding of our own identity. A counter-story positions itself to challenge a number of master narratives that present varied fragments of our shared cultural heritage. Master narratives are often archetypal, consisting of recognisable plots, schemas and stories. Oppressive master narratives cause doxastic damage in distorting self-image and self-identity. They also involve a recognisable repertoire of character types that can be positioned to fulfil the narrative requirements of the teller. Master narratives are not single unified stories but often present as ensembles of repeated themes. Counter-stories can gain cultural traction by highlighting the inconsistencies present within the ensemble of elements that have generated the master narrative.

Nelson (2001) argues:

“that through their capacity for narrative repair of identities damaged by oppression, counter stories can provide a significant form of resistance to the evil of diminished moral agency” (p7).

This can be operationalised in a number of ways, including highlighting oppressive aspects of master narratives that may be used by dominant groups. If the counter-story can hold its own and move the dominant group to acknowledge the full moral agency of the oppressed group(s) then there exists a space to acknowledge and exercise agency more freely. There is also a space for the oppressed to alter self-perception. Thus counter-stories *“are then,*

narrative acts of insubordination" (p8). They attempt to counter the dominant stories that may silence and marginalise alternative and more positive manifestations of narrative life. Counter-stories attempt to recover moral agency and need three credibility criteria including correlation to action, a strong explanatory force and heft. Counter-stories need to set out to repair the group identity as well as personal identity. In order for a counter-story to be effective, not only must it move the dominant group to reject the master narrative, it must also convince the affected subgroup(s) whose consciousnesses are infiltrated by the same master narrative (Nelson 2001 describes this as "infiltrated consciousness"). The counter-story must be accepted as identity-constituting. The important element to these stories is that they:

"don't just offer a different but equally viable way of representing you. To one degree or another, they resist a representation. Counter narratives set out to repair damage to an identity. The proper target of a counterstory is a master narrative that has been generated by an abusive power system to impose on a particular group an identity the system requires" (p155).

Nelson (2001) further describes and defines the nature of counter-stories and articulates the elements that must be present for this definition to apply. The stories must be identity-constituting and correlate to a type of master narrative in which this relationship reveals elements of resistance. The master narratives that are challenged must relate to oppressive forces within an abusive power system and any counter-story must attempt to repair this damage to identity and moral agency. Finally, counter-stories act as a moral self-definition even if this is not an explicit motive in its generation. These counter-stories could be master narratives but they do not oppress the individuals they identify. When Helen is advocating

for her husband and not letting health staff forget him, she is advocating and positioning him as someone with a strong moral self-definition, she is accounting for his moral competence. This positioning was a common feature in all of the participant interviews. The better they managed to narrate the care recipient's life and present this to an external audience in a coherent, unified way, the greater the impact on the moral recognition required to engage effectively in formalised service provision. Kaufman (2006) has commented that

"dementia has entered the domain of the ethical because the 'fact' of the person can be questioned and because, often, death is a matter of a decision. One must choose" (p27).

The carer's (in)ability to navigate this narrative tightrope holds them captive: they may lose their freedom to act and therefore may compromise their positioning as fully formed moral agents. This has the effect of reducing and limiting full moral agency. Nelson (2001) articulates three levels of resistance when engaging in contesting master narratives. Firstly, a refusal, in which the person denies that it applies to themselves. Then repudiation, in which self-understanding generated from a counterstory is used to oppose the master narrative. Finally, contestation, which implies an opposition to a master-narrative with a counter-story that is both politically and systematically approached. Within the carers' of this study, opposition with master narratives was often fragmented, partial and incomplete.

The data of participants were most closely associated with refusal and repudiation rather than contestation. This may be for a number of reasons both practical and ontological. On a practical level, these carers were often situated in co-ordinating and supporting their care recipient with minimal formalised care provision. Those who actually utilised services were often attempting to co-ordinate and navigate services in order to maintain carer integrity

and moral adequacy. This extended to gatekeeping formal carers and assessing their competence to care within community settings (Orpin et al 2014). How carers' network is an important issue: often carers do not have pre-existing networks to automatically access but rather they position themselves at both micro- and macro-level in order to extend and negotiate caregiving (Egdell et al 2010). Within this vulnerable group with already high levels of burden (Lavarone et al 2014; Miller et al 2013; Rikke & Birkelund 2013) related to dementia care, trying to navigate cancer services allows little systematic and organised opposition to master narratives. On an ontological question, the generation of clear-cut levels of resistance is problematic within a context of "small" stories within a narrative approach (Georgakopoulou 2007). Bamberg (2006) has convincingly argued that one works from two levels of positioning, from the context of story orientation and the co-ordination and interaction between speaker and audience. In doing so we are positioned to examine the ideological stances (master narratives) within which narrators are positioning a sense of self. While accepting the validity of such an approach, small stories, contextual, situated and partial, operate and fluctuate from multiple positions within a dialogue and social interaction. There appears a tenuous association from the constructions within participant dialogues to a systematic fully formed opposition characterised by Nelson (2001). Narrative inquiry is concerned with 'little science' (Denzin 2008) and this necessarily is local, historical emergent, contradictory and often accidental. The urge to control data and categorise them into levels of resistance appears unwanted and unnecessary. Resistance was manifest throughout the positioning of participants within the interview data but this fluctuated and was contingent upon the historically situated dialogue.

5.7 Co-ordinating cancer care, contesting carer identity

Cancer care requires significant co-ordination since it often involves multiple treatment modalities. The issues raised that cause problems for patients and families can be characterised as a lack of information transfer between primary and specialist care, a duplication of tasks or services, poor discharge planning and provision of conflicting information from different health professionals (Seal et al 2015, Walsh et al 2010). The importance of a key contact person was also a significant factor in good co-ordination of care. The participants experienced most of these challenges but this was exacerbated by navigating the system with a care recipient living with cognitive impairment. When Lauren describes the embarrassment of her father in outpatient clinic this was generated by a constant requirement to reiterate his previous medical history. The stigma associated with his inability to recall such information was a key issue and at times required Lauren's father to proactively challenge the medic(s), insisting they look at his medical notes for the background information. Lauren also described a situation where she dropped her father off in outpatients for a pre-surgical assessment. The clinic nurse contacted Lauren since he was not waiting in the appropriate place for that clinic. Her father also had a hearing impairment so he did not hear his name and Lauren had to return to hospital to find her father just round a corner to the clinic. There appeared no accounting for the vulnerabilities and co-morbidities that an ageing population often presents. Both Lauren and Alice specifically position this requirement to recall biomedical information throughout the treatment journey as a particular challenge and source of both contesting the carer identity and the moral agency of the care recipient. Lauren asked the listener why her father went to pre-op assessment only to be asked the same biomedical information in the anaesthetic room. In

this situation, he was anxious and did not have the cognitive abilities to answer the questions appropriately. For Alice, she was prevented from going into the anaesthetic room and she presented a situation where staff had to find her in the hospital in order to address the pre-op questions required. Both these examples of atrocity stories highlight a system that actively excludes and fails to assess the needs of patients with memory problems. Helen manages the situation, presenting the proactive, assertive position of a competent navigator. She positions herself to maintain moral adequacy and preserve the moral agency of her husband. There is general lack of carer involvement within acute care with people living with dementia (Jurgens et al 2012; Dewing & Dijk 2014), and instigating a person-centred approach can be challenging for health professionals (Moyles et al 2010; Clissett et al 2013). The experience of Betty in attempting to manage her partner's discharge was another area where co-ordination appeared hampered by inadequate communication. Betty had positioned herself as a victim of an unresponsive system, presenting a narrative of tragedy through a series of atrocity stories. The psychological distress of such encounters can cause immense distress, as Charon (2006) comments:

"The emotions of shame, blame and fear. These emotions among others saturate illness and add immeasurably to the suffering it causes" (p22).

Without explicit acknowledgement and examination of such narrative distress (by health professionals) stories remain untold and exiled to the wilderness of an unheard narrative. In the case of Alice, the lack of communication is well documented within the literature, with Bauer et al (2011a, 2011b) highlighting a paucity of discharge information for carers of people living with dementia. This included information about the patient's condition, care requirements at home, medication needs and general psychological support. Instead of a

narrative exploration of these areas, all that seems to occur is a minimal requirement for biomedical data communicated between health professionals from secondary to primary care. Often this is to the exclusion of the carer. There was also a sense, with the carers in this study, that a cancer diagnosis was more reason to urgently engage with formalised services. This is in contrast to carers of people with dementia alone, who felt nothing substantial could be done or support given with engagement with formalised care services (Stokes et al 2012).

With all the participants, the wider cultural context of caring and supporting someone older, with dementia and cancer, was an important element. This is particularly true of the palliative nature of much of the experiences presented. Howarth (1998) has argued that older people's deaths are viewed as unproblematic, a natural event, straightforward and offset by a long life. There is a perception of disengagement by older people on reflection of impending death. Howarth (1998) noted that her data challenged this by suggesting that it is a *"form of engagement with the present ... radically different from the goal-orientated engagement of youth or middle age"* (p676) and not a social withdrawal. Living with dementia is often living in the present and the narrative world of the carer becomes smaller, focused on day-to-day events that punctuate, form and guide their frame of reference. This common disengagement narrative has social consequences, with Lloyd (2004) suggesting that this narrative leads to an assumption that older people are not in need of specialist care and support since they know how to die, their proximity to death giving appropriate, and 'specialist' insight into dying. In this construction, palliative services are best channelled into supporting premature death since it is unnatural, tragic and requiring greater support.

Johnson et al (2015) highlight that disease prognosis is a more significant contributor to greater stigma than the Alzheimer's disease label:

"expecting the symptoms to get worse, regardless of disease label, led to significant higher levels of expected structural discrimination, pity and social distance" (p125).

Therefore, negative reactions to the person living with early stage dementia were more focused on the expected prognosis linked to that label rather than the label itself. Lloyd (2004) also makes the point that older people often have complex health needs and unpredictable dying trajectories that can be interpreted only retrospectively. This uncertainty was a constant feature of my participants' narratives and made the formal organising of care challenging and problematic for them. The recognition of the impending death of Betty's partner is an example, in which health professionals failed to foresee his dying to the point of arranging discharge on the day of his death. The ambiguous position of liminality situated by the dying is compounded by a narrative of having a 'good innings' related to older people. In such a cultural frame the moral claim to access support of others is both tempered and mediated for older people (Sweeting & Gilhooly; 1997). Healthcare professionals may perceive death as more of a technical defeat but patients may see death as both "unthinkable and inevitable" (Charon; 2006, p22). The fear of decline was a feature of a number of participant interviews, with both Jane and Lauren positioning their fathers as challenging their role of carer by resenting the supervision of them. The surveillance of the participants, in checking and watching their behaviour for signs of decline, appeared a source of conflict between carer and care recipient. This may be particularly significant, since Bowling and Gabriel (2007) examined lay theories of quality of life in older age and found that someone's freedom to do what they want to do without restriction was a key

indicator of quality of life. The participants highlighted the resentment that this often caused and the moral ambiguity for them as they attempt to maintain their moral agency in the face of opposition from care recipient and at times formal care services. Lloyd (2004) reminds us that increased dependency is inextricably linked with a loss of autonomy within contemporary western society but this construct grounded in individualism has further implications:

“the needs of older people at the end-of-life should be considered, not only in relation to their individual rights and claims but also in relation to their connectedness to others and the ethics of practices concerned with their care and well-being. The inter-relatedness of human beings and the importance of the social context has been overlooked in the pre-occupation with individual rights” (Lloyd 2004; 247).

The participants challenge the culturally framed discourse(s) of individualism with dementia troubling our understandings of autonomy as inherently good. This difficulty in handling these challenges was evident in the narratives surrounding confidentiality, with Betty finding it increasingly difficult to access information about her partner from health professionals whilst he was in hospital. Jane phoned the hospital to find out about her father’s health status and was told she would have to speak to her mother (even after telling the nurse that she also had dementia). This was in spite of Jane’s power of attorney. Both Betty and Jane were kept in the periphery of social life, isolated from involvement in caring relationships due to the underlining ethical framing of autonomy and the biomedical narrative(s) characterised by Mattingley (2010). The palliative nature of dementia also highlighted for the participants the challenges of facing mortality, frailty and ultimately

death that surround us but rarely penetrate the consciousness of our everyday life. As Frank (2009) comments:

“Illness threatens because it cancels our plans, forecloses our hopes and reminds us that on the most basic physical level, we have no control over our lives. Humans know, abstractly, that every heartbeat is a hope for the next one. Illness transforms that abstract knowledge into a constant, gnawing awareness” (p188).

In clinic, Lauren supports her father in impression management to cover up his cognitive impairment, but also this dialogue involves what Charon (2006) describes as “aspects of the self closest to the skin”. The multiple roles and positions that we perform in everyday life are stripped away, superfluous to requirements in order to get down to the essential core, the embodied self. Without the body the self is an abstraction. The participants are compelled into a world away from the “silence of health” (Charon 2006; p88) and, like Jane, attempt to navigate multiple health appointments, treatment choices and the aetiology of the disease process and what this means to their care recipient. For Jane, Lauren and Betty in particular, “as it takes away, illness also gives searing clarity about the life being lived around it” (Charon 2006; p97).

Tronto (1993) has conceptualised care from a feminist perspective and argues that care is a process with five stages: attentiveness, responsibility, competence, responsiveness and integrity. Attentiveness involves noticing what is going on and acknowledging there is a need. The perceiving of a need does not necessarily mean that this will progress to the second stage of responsibility. This is dependent on issues like duty of care or whether an individual feels responsible for meeting that need. The third stage is competence and reflects one’s individual ability to organise resources, whilst the fourth is responsiveness and

this posits an ethic of care from the standpoint of the care recipient. The final stage, five, is related to the integrity of care that can be measured by the extent that the previous stages have been engaged with and taken account of. In terms of the participant's familial ties this led to both attentiveness and responsibility as an obligatory response in order to maintain moral integrity. Competence was a challenging issue for a number of the participants with, for example, Helen successfully navigating and advocating for her husband throughout his ongoing cancer treatment. The contesting of their role as carer by the care recipient was an issue for Betty, Lynne and Alan, Lauren and Jane. This led to conflict within their relationship and also in positioning themselves to formal service providers. Attempting to provide a different, alternative narrative to the one presented by a care recipient to a health professional was restricted by both the confines of a time-pressured outpatient clinic (or any clinical encounter) and an understanding of autonomy that negated the social networks to which we all belong to. The competence to speak to health professionals was challenging even for those participants who had power of attorney and gaining access required careful and often rehearsed statements about the social or medical history of the care recipient. If this performance was adequate then the positioning of confidentiality or discourses surrounding mental capacity were not utilised to shut down communication. The fourth stage of Tronto's (1993) staging, responsiveness, was a challenging area for the participants because this often involved conflict and more surveillance or intervention as cognitive impairment affected safety and increased risk. This was sometimes in opposition to the care recipient who had limited insight into the extent of cognitive impairment. The morally ambiguous nature of keeping watch and in effect reducing autonomy at times was a key concern. For example, Lynne described the dilemma of whether to contact the DVLA and cancel her brother's driving licence and whether to hide his keys because she felt he was

unsafe to drive. If as Tronto (1993) suggests, these stages equate to the integrity of care then maintaining moral adequacy for carers can be problematic in terms of both competence and responsiveness, both of which require consent and support beyond the control of a carer.

Bauman's (2004) work on identity is helpful; he asserts:

"identity is revealed to us only as something to be invented rather than discovered; as a target of an effort, 'an objective'; as something one still needs to build from scratch or to choose from alternative offers and then to struggle, though for the struggle to be victorious, the truth of the precarious and forever incomplete status of identity needs to be and tends to be, suppressed and laboriously covered up" (p15-16).

In this sense Bauman (2004) appears to be astute in acknowledging the contested nature of identity work and this holds resonance within my data, carer identity appearing negotiated within a contextual, situated practice. The positioning of my participants and the efforts to maintain the moral agency of both their own identity and that of their care recipient highlights the precarious nature of such work. Bauman reminds us that identity is a hotly contested concept. He describes identity as created within the turmoil of a "battlefield" and

"identity is a simultaneous struggle against dissolution and fragmentation; an intention to devour and at the same time a stout refusal to be eaten" (p77).

The positioning of the carers was a moral requirement but open to misreading, misinterpreting and narrative fragility. Presenting such identity work in order to support care recipients requires narrative competence and some of my participants were more able to mediate this than others. The term 'carer' has been contested within the literature.

Whilst care is often viewed as a positive altruistic concept, the cared for are positioned as dependent and, as Fine & Glendinning (2005) remind us, “dependency is cold and its connotations are almost entirely negative. Those identified as dependent are assumed actively to seek to reverse this status” (p613). Tronto (1993) has argued that this construction of dependency should be challenged, with acceptance of help a positive adaption strategy that maximises quality of life and is a fundamental aspect of social life. It is prevalent in early childhood, illness, disability and frail older age, an integral part of being human. Molyneux et al (2011) assert that the term carer and the needs of carers are often highlighted without recourse to the structural inequalities that increase the existing burden. Policy would be better addressing the undercurrent of social prejudice, the cultural framing of narratives that create these gaps in statutory services. Situating carers as the focus of concern positions the carer as the primary moral agent to which responsibility can be handed over. It can further isolate the caregiver within the domestic situation, generating further vulnerability. O’Connor (2007) presents a similar interpretative framework to the one I have used, viewing the caregiver as a position rather than a role. It is a socially constructed process that is operationalised in the dynamic interaction within social encounters. Defining oneself as a caregiver is not neutral but enacts a series of culturally embedded narratives through which caregivers appropriate a new language for understanding and generating a sense of meaning to their actions. This process forms self-identity and is almost required when engaging in formalised care services. Without the attached tag of carer, being recognised by health professionals is more challenging, as are certain types of relationship such as non-familial carers or unmarried couples. Betty’s communication with hospital staff regarding her partner was problematic outside of marriage, Jane had difficulties since her father’s next of kin was his wife who also had

dementia but without capacity. However, in O'Connor's study most of his respondents had a delayed awareness of themselves as carers and it did not occur to them that they were doing something outside the bounds of their relational role. This has resonance with the work of Scott et al (2016) in examining narratives in those with asexual lives in which they describe stories of non-becoming. There is an implicit assumption that actors follow identity careers with a process of learning how to play a role and present a self: however, there are those who do not become something. They do not demonstrate resistance to the identity of carer or positively take up that role. As Scott (2016) comments:

"The process of identity repudiation and dismissal involves "non-events" and "non-issues" which are significant in their unremarkableness. Traversing these nebulous objects involves erratic journeys compared to the linear logic of becoming. Crucially, however, these are still socially negotiated processes, mediated by interaction with significant "career others" (p4).

Within my study there was both a sense that caring is just part of normal familial ties and a more consciously thought-through strategy since the navigation of cancer services often required a formalised self-identity as a carer in order to maintain the moral integrity of the care recipient. O'Connor (2007) suggests that self-identity as a carer develops as the care recipient deteriorates and this shift is often resisted since it represents a change to the mutuality of the relationship. He describes several of the carers in his study recognising that they were "taking over everything". This was acknowledged by a number of my participants and troubled their moral adequacy. There were other similarities and, in particular, most of the participants did not position themselves as a caregiver as something that was sought, embraced or consciously taken on. This reflects the wider literature reflecting the ambiguity and multi-faceted nature of identifying oneself as carer (Camden et al 2011; Egdell 2013).

The positioning of the identity of caregiver was important to my participants because it provided a context for making sense of their own behaviour and that of the family member. It also created a self-identity in order to advocate and to speak from authority by recognising the situational nature of the mechanics of care, often much broader than any attribution to personal responsibility. The identity as caregiver was also using concepts that were more familiar to formal services and hence access to support could be more straightforward by naming oneself as a carer.

Another element identified by O'Connor (2007) that directly related to the positioning of a number of my participants was the tension inherent in the distance-making narrative of the caregiving storyline. The separation of carer and care recipient attempts to objectify the familial relationship that binds the caregiver to the cared for. This can be a useful tactic in which to position oneself in order to survive the emotional intensity of a situation of nobody's choosing. Susan, for example, presented, a 'rational' question surrounding the foreclosing of her father's and mother's future narrative(s) and whether a quicker death would be preferable. This homicidal ideation in family carers has been noted in the literature and highlights the burden and despair that situates such discussion (O'Dwyer et al 2015). O'Dwyer was able to objectify the person in order to assess the situation. The tensions surrounding the power dynamics was also evident within the discussion with Susan, and the challenge for her was in assuming responsibility while making it look as though she was not. Within this performance Susan co-opted the formal carers who supported her parents as well as the medical team within a hospital context.

5.8 Stigma

Stigma has been defined by Goffman (1963) as an “attribute that is deeply discrediting” and defines the bearer “from a whole and usual person to a tainted discounted one” (p13).

Stigma leads to a ‘spoiled identity’ and can affect the person’s willingness to seek a diagnosis, receive support and socially engage with others (Gove et al 2016, Koch et al 2010, Bradford et al 2009). Ballenger (2006) suggests:

“Stigma is the amount of anxiety surrounding the boundary between the normal and the pathological, stigma is directly related to the social stakes of a particular set of behaviours or symptoms that are judged to deviate from some notion of normal” (P114).

Conceptually stigma is a difficult concept to define but can be categorised as the relationship between the understanding of the topic of stigmatisation (stereotypes), the attitudes towards a stigmatised individual and the expression of the discriminatory behaviour (Thornicroft et al 2007, Goffman 1963). Werner et al (2014) carried out a meta-analysis of published papers and conceptualised stigma as focusing on an individual, family, professional and social level. Among my participants stigma seemed to be a feature of the participants’ care recipient, with Jane, Helen and Linda all describing situations in which their loved one attempted to conceal or cover up their diagnosis from others (Aminzadeh et al 2007). These acts of concealment are a conscious and intentional response to perceived stigma and the need to “pass” (Goffman 1963) within the context of health professional contact. Rather than being discredited, the care recipients have attributes that were discreditable with the potential to be stigmatised if found out. There was a question mark over whether, if the dementia were revealed, it would affect the performer’s authority to give the actual performance itself. Could the clinician believe anything Laura’s father said

after a disclosure of dementia? This is all the more threatening since, as Goffman (1959) comments,

“it may weaken in our minds the moral connection between legitimate authorisation to play a part and the capacity to play it” (p59).

This performance is fostered and sustained by the intimate co-operation of more than one participant and the carer’s attempt to present a front that protects the moral agency of their care recipient. There is a fragility in performance since it requires an expressive coherence that may be compromised because, for example, of cognitive impairment. The need to avoid drawing attention to facts that may compromise, expose or discredit the performance and impression is an important area of attention. “Destructive information” must not be conveyed to the audience of the situation that is being defined for them. These become “dark” secrets, facts that are incompatible with the image presented. Lauren, for example, has to make decisions about how to position her father within encounters with health professionals. Does she maintain her father’s attempts to “pass” or does she intervene when his performance prevents the addressing of important care and safety needs? This becomes an ethical question and one that navigates a fine line between moral agency and moral responsibility. The decision is, as Goffman (1963) comments, *“to display or not to display, to tell or not to tell, to let on or not let on, to be or not be and in each case to whom, how, when and where”* (p57). Lauren’s fear is the conferring of a master narrative whereby having dementia would carry cultural scripts that could compromise care and lead to assumptions about quality of life, treatment choice and moral agency.

The concept of stigma has been further categorised by Goffman (1963) to include self-stigma, public stigma and courtesy stigma. Self-stigma relates to the internalisation of ideas

whilst public stigma refers to the reactions of laypersons toward a stigmatised individual or group. Courtesy stigma (stigma by association) encapsulates the emotions and beliefs of those surrounding the stigmatised person (Larson & Corrigan 2008; Werner et al 2012). In terms of my participants, Werner & Heinik (2008) indicate that family stigma is especially significant in preventing caregivers from seeking services, however much the diagnosis of cancer necessitated carer engagement with formalised services. The fact that these services were not specialist in dementia care made protecting the moral agency of the care recipient challenging. MacRae (1999) found that a significant number of her sample claimed not to have experienced stigma or were concerned with avoiding it but again within my dataset participants were obligated to engage with many cancer services that were often not configured to, or accommodating of, people living with cognitive impairment. There was therefore evidence of 'covering' practices (Goffman 1963) since the stigma often became visible or, if it was known about, there were attempts by both carers and care recipients to minimise the impact. "Covering" practices were common because of the complex nature of much of the cancer treatment; for example, Lynne's brother was required to have sixteen fractions of radiotherapy and the logistics of organising this were challenging. The impact of his dementia required both disclosure and treatment adaptation, both of which were problematised by Lynne and Alan since the consultant did not wish to admit him for treatment and his mental capacity was not assessed upon his initial refusal of treatment. Werner et al (2010) further articulate three areas of family stigma including caregiver stigma, lay public stigma and structural stigma. These relate to the elements of cognitive attributions (the stage of the disease and perception of danger, for example, Howarth (1998) characterising older people's perceptions of a 'bad' death as a lingering, painful one involving loss of physical or mental abilities, becoming a 'non-person' or 'just a body'. There

are emotional reactions (articulated as both positive, such as compassion, and negative, such as shame) and behavioural responses (such as distancing and concealment). Werner et al (2010) found that the greatest impact on caregiver burden was family stigma. Shame as an emotional reaction is common with courtesy stigma and a challenge (particularly with adult children). This led to decreased involvement. The participants within this study did not and could not disengage from their care recipient but had to actively maintain their moral agency by impression management and advocacy work precipitated by the cancer diagnosis. The difficulties with 'passing' within clinical encounters was hampered by the complexity of cancer treatment regimens and the multi-agency approaches that required carer positioning as the key worker. The advocacy work described by Helen, for example, was foundational in providing a person-centred approach to her husband in which moral adequacy could not be maintained without navigating the cancer journey.

Issues surrounding stigma were one of the reasons I used the term "memory problems" rather than dementia on the participant information sheet. This was initially suggested by the work of Bartlett (2012), who found memory problems was a more acceptable term than the word dementia with its associated stigma. This was also to take account of the diagnostic uncertainty since someone could have memory problems without a confirmed diagnosis and I did not want to exclude a carer in these circumstances. There is a sense where perhaps using this terminology is reinforcing the stigma associated with dementia, and 'reclaiming' the term would present an opportunity to confront the negative discourses that culturally frame dementia. This challenge is rooted within terminology, the literal Latin meaning of dementia being 'without mind' (Chiu 2005). It is often used as an insult in western societies, and Gilmour and Brannelly (2010) give the example of the popular Harry

Potter novels with the ‘dementors’ sucking positive emotions out of humans, a derivative of the word “demented”. Sachdev (2000) has gone further to suggest that dementia as a term should be jettisoned as a irretrievably negative label, with cognitive disorder, prefixed with a form such as Alzheimer’s or vascular, as a less culturally loaded medical category. Carers in Stokes et al’s (2012) study felt that the link of dementia to mental health services exacerbated stigma and reinforced the negative stereotypes of people with dementia by association with people with severe and enduring mental health problems. Therefore, not only the term dementia was stigmatising but also the specialist mental health services assigned to support this population group.

5.9 Narrative care

There has been a call for a narrative turn within healthcare and a troubling of “large healthcare” (Bohlmeijer et al 2011). Within this paradigm the importance of meaning and storytelling takes centre stage, rooted in solidarity and an emancipatory ethic. Health professionals develop narrative competence within daily practice to varying degrees. Charon (2004) has defined narrative competence as the

“set of skills required to recognise, absorb, interpret and be moved by the stories one hears and reads. This competence requires a combination of textual (identifying a story’s structure, adapting its multiple perspectives, recognising metaphors and allusions), creative skills (imagining among interpretations, building curiosity, inventing multiple endings) and affective skills, (tolerating uncertainty as a story unfolds, entering the story’s mood)” (863).

In this sense, narrative competence becomes the ability to co-create, to co-imagine healthcare decisions that reflect both scientific knowledge and metaphoric or narrative

knowledge by which we generate meaning within life events. Narrative care develops a “language of opening” that serves as a counterpoint to the medical model’s “language of limits” (Vittona 1999). Vittona (1999) reports on the nursing assistant’s use of language in a residential facility for people living with dementia and how they use a process of

“naming and refraining to construct a set of social meanings that depict the residents as a socially responsive actor with a surviving self that is living, not just waiting to die” (p362).

This process was a nuanced counter-narrative positioning experience, indigenous knowledge and the empirical world to sustain personhood in the face of reductionist biomedical interpretations. It also situated the lived experience within the context of a dedicated care facility organised around biomedical presuppositions about the nature of dementia care. This reframing was characterised by the “local knowledge” that guided the care of residents as well as general attitudes of staff towards the care home. The nursing assistants were able to generate a narrative life for residents and were aware of the embodied language of individuals, interpreting those meanings and engaging in a dialogue with the residents. The language of openings typified the staff’s way of talking, being and doing in maintaining personhood: for example, the language of ‘wandering’ was reframed to focus on ‘getting busy’, ‘moving’ and ‘walking’. Vittona (1999) comments that this

“alternative language reflects what I will call ‘rhythms of the social world’ of the residents, where movements are far from meaningless or aimless” (p371).

The biomedical framing within medical encounters narrative is a key concern within narrative care and this permeated the interview with Lauren. She eloquently described the positioning of herself to support her father in maintaining moral adequacy. This was

achieved by a series of manoeuvres and deceptions to minimise the impact of his cognitive impairment within outpatient clinics. When Lauren the carer and daughter is silenced in outpatient clinic, Lauren the storyteller brings her back to life and reanimates her position and the ethical framing that is generated. Frank (2004) highlights a protocol-driven system that fails to examine the cultural frame in which it is heard. If the answer to a question does not fit with health professionals' expectations then patients could face difficulty getting the care needed. People who care for other people do not test them, so why do the medical staff keep asking Lauren's father about his medicines or medical history? Why not just look in the medical notes?

Mattingley (2008) reminds us that narrative is connected to our capacity to read other minds, what she describes as narrative mind reading. Interpreting intentions is precipitated upon our capacity to situate actions within unfolding narrative frames. The interpretative act requires a capacity to assign motive within a situated unfolding story and, as Mattingley (2008) comments,

"Narrative mind reading as tacit practical understanding has strong kinship with the speech act of storytelling in which a narrator explicitly links actors, motives, acts and consequences in a causal chain, often precisely for the purpose of determining who is responsible for the results" (P137).

One must be able to categorise or recognise an action within some sort of historical context in order to make it intelligible, it must be positioned within a culturally shared story.

Narrative mind reading becomes an everyday necessity in sense-making and is culturally situated and integral to the production of cultural knowledge. When we are presented in a context where there is ambiguity and uncertainty, when it is not clear why people are acting

in a certain way or what exactly is going on, then a failure in narrative mind reading may occur. When clinical interchanges do not go well it is often because of misreading(s). For my participants, when Lynne and Alan position the consultant as dismissive of their brother's right to a modified treatment plan or when Betty positions the staff on a surgical unit as unresponsive to her concerns then this can lead to a series of atrocity stories. When treatment and support by health professionals are perceived in a more positive light, often family caregivers like Helen are able to "read" each other adequately enough to generate a common, shared narrative. The complexities of care are often minimised within formal healthcare interactions and this can create narrative foreclosure and ineffective support. Alice's narrative(s) particularly highlight this. For Alice, she presents a clear conflict between herself and her family and the decision of the consultant to keep her husband in hospital. The medical team were following a common script of "healing as sleuthing" (Mattingley 2010). They were not satisfied that the clinical picture represented a terminal stage, irreversible and futile to treat. Alice became a "problem carer" actively impeding the medical journey to restoration. This is not merely a misreading of story lines, a misinterpretation by the consultant. The medical team are almost inevitably drawn into the plot of a problem carer because of a number of competing circumstances. Alice was older, unable to navigate healthcare systems and reluctant to ask questions. Her contact with formal care providers was limited and she disputed the positioning of her husband as aggressive and uncooperative. Alice's encounter becomes the plot of a "troublesome familiar stranger" (Mattingley 2008; 145) in which the characters are presented as acting in predictable but unreasonable, unaccountable and possibly immoral ways. Their characters are rendered flat, stereotypical and nameless. Alice could not account for the actions of the health professionals who were at one stage talking about discharge and then refusing this

course of action. Equally, the health professionals were positioned by Alice as appearing unable to see her narrative, to see the care and nurturing she wished to do in her husband's last weeks. Why was it that only she and her daughters could recognise his dying? Charon (2006) reminds us that:

"Non-narrative knowledge attempts to illuminate the universal by transcending the particular; narrative knowledge, by looking closely at individual human beings grappling with the conditions of life, attempts to illuminate the universals of the human condition by revealing the particular" (p9).

Mattingley (2008) uses the example of the medical chart but her reflections remain analogous to the experience(s) of Alice. Medical charts are records of small moments here and there, they are highly abbreviated, multiply authored and string together short happenings without an integrated, coherent narrative plot. The complex narrative meaning(s) that story our lives are replaced by a series of "nows" that are separate and discrete. Medical charts generate a clinical gaze that is impervious and actively excludes motives. The evaluation of actions and subsequent consequences is disconnected from a narrative cultural frame. Mattingley (2008) asserts that:

"Because actual humans are not flat, narratives that portray them in this way can only be told if there are discursive strategies that allow 'real life' storytellers to ignore a great deal of what is actually done and said" (P147).

Charon (2006) has also reflected on the hospital chart as a genre, highlighting the controlled dictum, the prescribing of the grammatical tense and voice in which to write and record to the exclusion of emotion. By identifying a text's temporal scaffolding one can highlight the

narrative silencing that routinely occurs within formalised healthcare. Biomedical framing by this process often excludes the moral agency of all human agents. There is not the presentation of a counter-narrative described by Nelson (2001) but rather a refusal of narrative itself and the presentation of a chronicle in which it describes one thing after another, not one thing because of another. Kirmayer (2000) refers to this process as the creation of an ideological account, this turning and reconstruction of narrative gives a specific kind of coherence to a story. It also gives the health professional technical control over both interpretation and continuation of the story and reinforces the reality from which it draws its structure. Frank (2015) comments that effective narrative care requires proximity, the being there and listening to the stories with which we interpret our lives. This process is actively hampered by healthcare organisations in which honouring this commitment is troubled by persistent territorial disruptions over who stays how long and does what. Frank (2015) asserts that

“this structural disruption of continuity of relational care is more than an organisation problem; it is a moral failure of healthcare, deforming who patients and clinicians can be to and for each other” (p218).

Charon (2006) examines narrative knowledge within a healthcare context and suggests that such an approach requires candid reflection and an active listening to the stories that frame one’s life. She characterises the differences in approach between patient and health professional with the former perceiving illness within the narrative framing of their whole life whereas the latter tends to designate illness within discrete, isolated events framed as biological puzzles requiring expert medical or behavioural interventions. Charon (2006) suggests there are five narrative features of medicine: temporality, singularity,

causality/contingency, intersubjectivity and ethicality. Temporality refers to the time needed to generate “healing”, to engage in collective narratives through collaboration and listening. Without time to contextualise the plot and narrative, patients will struggle to maintain integrity and personal agency. Singularity highlights the unique nature of narrative encounters in both their originality and their irreproducibility. It challenges the medical impulse to universalise and replicate but rather focuses on the particular patient, demanding to know how a disease uniquely affects them, “what is different about this disease as it manifests itself in this particular patient?” (p27). The challenge remains for health professionals to mediate through the contradictory impulse to both maintain and honour the unique components of narrative construction and the requirement to generate observations that are ‘readable’ in a range of healthcare setting and personnel. Causality calls for a narrative structure and emplotment(s) that contextualise stories and make them culturally recognisable. Emplotment challenges the restrictive nature of medical discourses as Charon (2006) comments:

“unlike other impulses with which to face the unknown, the expropriative impulse, the imperialistic impulse, the reductionist impulse, the narrative impulse does not excavate the unknown beyond recognition. It does not sanitize it of danger; it does not consign it to sameness with other such predicaments. Nor does it take away from it what makes it itself or take it apart beyond putting it back together. It celebrates the uniqueness and respects the unity of the event while representing it. Expansive rather than restrictive, multiplying possibilities instead of reducing them, narrative practices enable the observer or the participant to live in the face of contingency without trying to eradicate it” (pp49-50).

Emplotment occurs throughout clinical practice, from diagnosis to nursing interventions and care plans. They are ways to manage and quantify a plot from an apparent disparate series of events or states of affairs. The categorisation of these set of events emplots it and makes it medically recognisable, it provides causality. The fourth narrative feature of medicine is intersubjectivity, and Charon (2006) argues this is essentially the interaction between two individuals. It presupposes that any act of reading embeds the narrator and reader in an intersubjective situation, a meeting between teller and listener. This is often based on complex texts shared between patient and health professional involving silences, words, physical findings and examination(s). Ethicality is imbued within narrative approaches since the coda of stories often hinges on a call to ethical living as either a question or an answer. Within Betty's narrative, how was her partner's dying not recognised? Why was Lauren's mother's moral agency challenged by referring to her as a "little demented lady"? These demand the listener to engage and present an answer, as Frank (2010) comments that "stories inform people's sense of what counts as good and bad, of how to act and how not to act" (p29). Stories are "people's selection/evaluation guidance system" (p44) and therefore they, like Betty, will position atrocity stories in order to guide and justify to the listener their ethically driven response. Narrative care can ultimately open up the storied lives of carers and care recipients in a way that engages with the meaning(s) which we attach to the disease process that confront us. In doing so this becomes a joint venture in creating hope, opening up silences and examining the contexts in which we live. If health professionals can honour this intersubjectivity then, as Charon (2006) suggests,

"They will know their patient's beliefs and wishes regarding end of life, if only as part of what they learn of their temporality. They will more regularly enter robust intersubjective

relationships with their patients, knowing with more accuracy and authenticity than other health care professionals do about what denotes meaning in each patient's life ... the ethicality of narrative medicine that is to say, emerges directly and organically from its practice and need not have a separate 'bioethics' function appended to it" (p210).

5.10 Implications of the findings to the wider literature

In terms of learning difficulties and cancer the literature identified poor communication, particularly with the person with learning difficulties and health professionals but also in conveying sensitive and complex information to professional carers (Tuffrey-Wijne et al 2009, 2010). This has resonance with my data in that poor communication and the exclusion of carers within the decision-making process were compromised at numerous point of the treatment journey. All the carers within this study felt at times that the staff working within oncology did neither understand nor proactively engage with the needs of those who are cognitively impaired. This highlights the need for more systematic training and support to meet the often complex co-morbidities and is reflected within the literature related to learning disabilities and cancer care (Flynn et al 2015; 2016). There are also issues of treatment pathways that do not respond to the co-morbidities within this population (Witham et al 2014). Addressing the needs of supporters or carers is important since they may be the central figure in interpreting the often complex decision-making processes and treatment regimens associated with cancer therapies (Sullivan and Hussain 2008).

Paternalism appears to be a feature of people with learning difficulties with limited involvement within the decision-making process. The data within this study appeared more nuanced in relation to paternalism. From a carer's perspective, supporting choice and autonomy often required complex positioning involving co-operation between, and

interaction from, health professionals or formal carers and their relative within any dialogue. So supporting decision-making in a realistic way that contextualises the implications and limitations of how dementia affects their relative remained challenging for carers. Maintaining moral integrity in supporting issues of choice, decision-making and quality of life was ethically taxing and often required careful consideration and reflection.

There appears larger cohort studies in relation to cancer and Severe Mental illness (SMI) and this highlights the poor survival rates following a cancer diagnosis of people with severe mental illness. This appears a consistent feature and replicated internationally in Japan (Ishikawa et al 2016), New Zealand (Cunningham et al 2015) Europe (Chang et al 2013, Ribe et al 2016, Tran et al 2009, Batty et al 2012), USA (Baillargeon et al 2015, Abdullah et al 2015, Bergamo et al 2014, Farasatpour et al 2013), Canada (Kisely et al 2008) and Australia (Kisely et al 2013). As with people with severe mental health needs, current literature highlights the poor survival rates following cancer diagnosis of people with dementia (Gorin et al 2005, Raji et al 2008, Robb et al 2008, Patnaik et al 2011, Chang et al 2014, Kimmick et al 2014).

The current literature characterises and suggests that the lower likelihood of cancer treatment for people living with pre-existing dementia is related to issues of quality of life and the additional staff time needed to support this population (Baillargeon et al 2011). Compared with other comorbid disease groups, patients with dementia tend to be diagnosed with cancer at an unknown or later stage compared to patients with cancer only (McWilliams et al 2017). The literature remains more circumspect in relation to the factors that contribute to poor survival with late diagnosis for both SMI and dementia reported

(Baillargeon et al 2011, Farasatpour et al 2013, Tran et al 2009, Ribe et al 2016, Ishikawa et al 2016, Kisely et al 2008, 2012). Cunningham et al (2015), however, report that late diagnosis was seen in those with schizophrenia or bipolar disorder rather than other mental health conditions. Chang et al (2013) further suggest from their data that associations between mental disorders and cancer mortality are more likely to be accounted for by differences in survival after cancer diagnosis than by delayed diagnosis. They suggest that studies like Baillargeon et al (2011) did not adjust for potential confounders in their analyses, especially for type of cancer. Interestingly Ishikawa et al (2016) found inpatient mortality rates were higher even for those with early stage disease; this would suggest other factors may be affecting outcome rather than late diagnosis. Any pre-existing illness can impact on cancer stage at diagnosis, with diagnostic overshadowing a possible cause (Howard et al 2010, Irwin et al 2014). Issues of risk management are also invoked with cognitive impairment, suggestive of compromised abilities to self-care related to side effects, complications of treatment and follow-up (Ballargeon[DIFFERENT AGAIN] et al 2011, Iritani et al 2011). This suggests slightly different areas of concern to those with SMI where non-compliance can be an issue as well as managing negative symptoms, for example social withdrawal and decreased expression of emotion in schizophrenia making informed consent challenging (Farasatpour et al 2013, Abdullah et al 2015).

Involving carers throughout the treatment journey for cancer was a significant variable in whether people with SMI completed treatment, and the 'background' work required by the carers within this study was integral to their relative's completion of cancer treatment.

Sharma et al (2010) have suggested that, within their cohort of patients with breast cancer, schizophrenia did not pose a significant treatment risk, with few participants declining treatment and effective support and communication being facilitative of this process.

Howard et al (2010) comment that standard procedure for radiotherapy is to lie still on a couch for consecutive days lasting for potentially weeks and these daily fractions can be stressful for people with SMI. The necessity to remain alone in a room during the procedure with automated instructions can generate anxiety for patients with a tendency for paranoia and auditory hallucinations. Other treatment issues like face masks to keep the head in position for head and neck radiotherapy and the claustrophobic nature of CT or MR scans can also be challenging. This has parallels with dementia care in terms of carers being often excluded from treatment procedures (CT/MR scans, radiotherapy) that can cause patient distress (Witham et al 2014). This issue was identified by a number of participants within this study; for example, Lynne's brother had issues with getting ready on time for daily radiotherapy and complying with treatment. Stigma may be a factor within cancer care for people with severe mental health issues (Irwin et al 2014, Ellison et al 2013), with people living with schizophrenia reporting high rates of healthcare discrimination (Thornicroft et al 2009, Thornicroft 2011). Stigma is also a common feature of dementia care (Behuniak 2011, Beard & Neary 2013).

The limited treatment options offered to people with severe mental illness highlighted by Bergamo (2014), Mateen et al (2008) and Kisely et al (2013) could highlight the disparities in care exacerbated by patients with bizarre affect or poor hygiene or when clinical uncertainty related to the best treatment (Jones et al 2008). If oncologists believe that people with, for example, schizophrenia would become too agitated, aggressive or non-compliant they may refer a patient to a more conservative sub-optimal treatment option. Participants in this study describe either long waiting times with no follow-up or little accommodation with the complex issues they face supporting someone with dementia. From the populations-based

studies and the speculative discussion generated there may be a number of issues which make the treatment journey challenging. The practical issues related to quality of life, treatment tolerance and behavioural or psychological issues that may compromise optimal treatment compliance applied equally to participants within this study (as to those with severe mental illness). The need for Carer support in trying to ethically manage these competing issues was the predominant finding in this study. Late diagnosis may also be connected to an inability to articulate health concerns in the presence of cognitive impairment (Iritani et al 2011) and the subsequent delay in seeking help.

There are clear challenges in acknowledging how to manage cognitive impairments by health professionals (Courtier et al 2016) and this also appears a feature of supporting people with SMI and learning difficulties in an oncology setting. How to work more widely with the network of supporters, carers, relatives and specialist social support agencies is foundational in meeting the needs of these groups. Within the literature base there are common issues between people living with cancer and either dementia, learning difficulties or SMI. Effective communication is central but remains challenging since complex co-morbidities can require contact with a wider social network of supporters including carers (paid and unpaid), relatives and specialist health teams. Conveying specialist information about cancer treatment or side effects and assessing patient and carer understanding can again present difficulties. This has implications for both patient safety and risk as well as compliance with treatment. Cancer therapies can be lengthy and complex and involve procedures that are psychologically stressful to people with SMI, learning difficulties and dementia. For example, radiotherapy, chemotherapy regimens and diagnostic scanning can all require a level of co-operation and adaptation not easily available within these

population groups. To address this problem health professionals within oncology settings would need to provide services that can adapt to the complex requirements of people with complex needs. This needs to be in tandem with the social networks of carers or supporters of people living with cancer and dementia.

Within the wider context of dementia care there are clear issues with the extremely high global burden and the grief and change required for informal carers in supporting the person living with dementia (Madsen and Rikke 2013; Lavarone et al 2014; Raggi et al 2015). This challenge was evident within all the interviews with the participants, and managing the issues related to dementia and supporting their relative through cancer treatment was a significant personal challenge. How the participants managed this process varied but flexibility and an acceptance of symptoms was important within daily life (Moore et al 2013). Particularly for Lynne and Alan, Susan and Lauren, the dementia rather than cancer diagnosis was the most significant issue and navigating cancer care and any subsequent treatment was often complex and ethically burdensome. These data have resonance with the work of Egdell et al (2010) in that there were not particular pre-existing networks that the participants automatically accessed but they all had to position themselves both at a micro and a macro level in order to extend and negotiate caregiving. Susan had to manage this with formalised care for both her parents, Lynne had to negotiate admission for her brother for radiotherapy and Helen had to work closely with ward staff to maintain her husband's well-being. Within a hospital context the experiences of the participants reflect the evidence in terms of carers feeling excluded from the decision-making process (Lord et al 2015). Furthermore, this also highlights some of the challenges of supporting someone with dementia, for example denial of the problem and rejection of help from the person

with dementia and from health professionals, the failure to recognise problems and claims of confidentiality and data protection that can exclude the carer (Livingston et al 2010). Due to the complexity of care required for supporting someone with dementia and cancer the carers within this study were expert gatekeepers, demonstrating reluctance to entrust any of their assumed responsibility as primary carer to others (Orpin et al 2014). They trusted and accepted a select number of formal carers or health professionals and remained hyper-vigilant in maintaining standards of care. For those participants, like Betty or Alice, who experienced poor care, there was a 'cycle of discontent' (Jurgens et al 2012) in which quality indicators like maintaining safety, hydration, food and meaningful engagement with their relative were important criteria. Lynne's experience of her brother in hospital and a lack of support for his hygiene needs also highlights the environmental barriers for people living with dementia. Her brother could not operate the taps or shower and the noisy, open spaces of a ward were not conducive to orientate him to his current situation. This in conjunction with increased surveillance, security and infection control measures can accentuate disorientation (Barnes 2006, Zuidema et al 2009, Digby & Bloomer 2014). Most of the participants' experiences reflected the literature in that acute care, essential physical care was prioritised (Cowdell 2010), there was a general lack of information for carers on their relative's condition, ongoing requirements, symptom monitoring and management (Bauer et al 2011a, 2011b) and carers felt ignored by staff (Jamieson et al 2016). McWilliams et al (2017) conducted a systematic review examining cancer and dementia and their implications for cancer-related care. They highlight the paucity of evidence in relation to palliative or end-of-life decision-making in patients with cancer and dementia. The findings of this research would suggest that, for carers, treatment goals are based on quality of life

rather than on curative intent, and this becomes an ethical driver for the participants of this study.

Chapter 6

Conclusion and implications for practice

6.1 Narrative approaches to clinical practice

Narrative approaches to care (Charon 2004) would implicitly apply person-centred decisions that occur in the situated context of daily practice. This approach seeks stories that characterise the lives of both carer and cared for and the nuanced interchanging of roles between mother or father and son or daughter, partner and partner, sister and brother. It moves beyond the tendency of personhood to be conceptualised as an individualised interpersonal construct rather than an examination of the wider socio-political context in which lives are situated (Bond et al 2004, Bartlett and O'Connor 2007). The lives of both carers and people living with dementia and cancer are affected by social forces that are more pernicious and embedded than issues affecting the immediate care environment or interpersonal interactions. Narrative approaches can bridge the micro/macro social discourses by implicitly addressing this: by articulating the grand narratives of biomedical frames of care, the personal thereby becomes political. Jones (2008) reflects the work of Denzin (1997) in asserting that personal narrative and storytelling become an obligation to critique, an ethical obligation to examine "subject positions, acts and received notions of expertise and justice with and outside of the work" (p. 219). It becomes an incitement to action predicated on a "plausible and lifeworld and charged emotional atmosphere as an incitement to act within and outside the context of the work" (p. 219). Stories *do* something, they are purposeful and can constitute a first step towards social change. They testify both to people's ability to re-engineer and contextualise stories to answer and generate meaning and to their ability to draw from the cultural framing from which all

narration derives. In answering this call to stories the participants in this study generate explicit, moving accounts persuading listeners intellectually and emotionally, and ultimately, as Jones (2008) comments, move “toward concerted social, cultural and political action” (p. 220). The narrative(s) within this study remain visceral, compelling and moving and often document atrocity stories. They speak of the social geography in which carers navigate, and the stories can identify and reveal the position(s) in which the participants place themselves.

Narrative mind reading (Mattingley 2008) is required by health professionals to avoid positioning people as ‘flat’ characters whose self-narrative becomes an insignificant subtext to the plot of diagnosis, treatment and recovery. The carers in this study also attempted to present counter-narratives (Nelson 2001) to some of the master-narratives described by both Frank (1995, 2015) and Mattingley (2008). The success of these counter-narratives and the positioning that took place was often based on challenging role assignment and the identity work required to support their relative with dementia and cancer. The health professional approach (in using a narrative knowledge) to the care dyad of patient, carer and professional is not an added benefit to care management but an integral component of interpreting lives in the presentation of health and illness. The five narrative features described by Charon (2006) are important to examine the singular, unique context of illness narratives and were particularly highlighted in the complex and challenging situations described by the participants in this study. How to honour the stories of patients’ lives is as much an implicit moral and ethical task for health professionals as it was an explicit moral and ethical task in the interviews with carers. A narrative approach is more nebulous and ethereal than presenting a concrete set of tasks for health professionals to undertake in order to respond to carers. There were obviously issues with the clinical environment which

made treatment more challenging, there was, perhaps, the need for specific protocols to examine the treatment journey for people living with dementia and a greater requirement to include both patient and carer in developing care planning within a cancer setting. There, however, were, more nuanced and underlying issues that led to atrocity stories and derived from biomedical approaches to care that excluded carer involvement, restricted narrative dialogue and led to communication breakdown. Addressing these issues is complex and requires listening and being attentive to the silencing of patients' narratives and the networks that hold and nurture the human identity that stories provide. Health transformation starts with small stories, counter-narratives that position themselves, gain traction and agitate for change in the face of narrative silencing.

The participants within this study were concerned with maintaining the personal integrity of their relative with dementia. The carers attempted to position them in ways that maintained identity in situations where the dementia could threaten and contest their identity. The findings of Courtier et al (2016) also reflect this and the negotiating required for carers relied on effective honest communication in order to articulate the complexities of the situation. Finding the opportunity to have these discussions was challenging for the participants. The stigma associated with dementia was exacerbated by the multiple and complex cancer treatment pathways that often challenge both carer and their relative with dementia. There appeared an inflexibility in adapting cancer treatment pathways to meet the needs of people with cognitive impairment, and this was further compounded by carer exclusion within this journey. Carers are the ones who attempt to forge connections and link past to present.

6.2 Anticipatory grief

Health professionals need to support this process of carer involvement and create systematic ways to include carers throughout the cancer treatment journey. This is of particular importance since anticipatory grief is common in supporting someone with dementia and associated with carer depression (Kiely et al 2008, Chan et al 2013). Indeed, compared to other long-term conditions there is evidence that carers of people living with dementia experienced twice as much anticipatory grief as, for example, cardiac disease carers (Ross and Dagley 2009). The carers' experience is different from supporting someone with cancer since they are exposed to multiple losses during different phases, with related guilt and anticipatory grief a common feature. They had also often said their farewells prior to the advanced stage and these appear different to the cancer carer experience (Albinsson and Strang 2003). Albinsson and Strang (2003) suggest that staff experienced in dementia care are more responsive and act as a go-between for patient and family and are more expert at supporting the maintenance of familial ties than non-specialist staff. The participants in this study were therefore not only exposed to loss and grief in relation to cancer but also to anticipatory grief as they support their relative with dementia. This grief is also within a context of increased caring responsibilities since usually carers of those with cancer have a short, intense, time when they are supporting someone through surgery or chemotherapy but the participants in this study had this responsibility as well as the long-term support needs of their relative with dementia (Kim and Shultz 2008). Within the context of dementia caregiving, anticipatory grief may include grief at the loss of roles, intimacy in relationships, loss of freedom, anger, isolation and fear about the future (Holley and Mast 2009). This may increase the feeling of burden and, whilst caregiving within the

context of cancer may invoke similar grief responses, it is the duration of these process in dementia care that becomes challenging, the “mini-deaths” (Marwit and Meuser 2005) of loss before the physical death of the person living with dementia. The extra difficulties appear to present to the participants in this study in the new immediacy of these emotional responses in relation to a second potentially life-limiting condition, cancer. There are now clear treatment pathways and options available that require decision-making and involve a whole new set of supportive strategies in order to safely navigate cancer treatment. In this context training staff to support carers to potentially adapt to those new demands would seem an integral requirement for carers to support the treatment journey of their relative living with cancer.

6.3 Decision-making

Decision-making was an important issue generated and highlights the challenges of substitute decision-making within the context of dementia and cancer care. The carers in this study often felt excluded and this reflects the findings of the wider literature that carers of those people living with dementia often felt excluded from decisions made in hospital and those who felt unsupported by professionals found decision-making more difficult (Livingston et al 2010, Lord et al 2015). Decision-making with the person living with dementia is complex; requiring carer negotiation and nuanced communication that often needed adaptation dependent on the severity of the cognitive impairment (Miller et al 2016). There was often a continuum with a gradual transition from supported decision-making to substitute decision-making (Sami & Manthorpe 2013). Conveying complex treatment information about cancer occurred without meaningful health professional engagement. There was limited information giving or involvement even when one

participant had lasting power of attorney for their relative with dementia and hence a legal right to be informed. This highlights some of the legal issues confronted with decision-making and capacity since in England and Wales the Mental Capacity Act (MCA) 2005 codified existing clinical practice to specific decision-making on behalf of adults lacking capacity. There is evidence that this legal framework is still inconsistently applied in practice (Hinsliff-Smith et al 2017) and claims to confidentiality and data protection as well as bureaucracy and rigidity also meant that carers' ability to make decisions was sometimes compromised. Bayne and Preston-Shoot (2017) highlight that there are fundamental flaws in the way the MCA (2005) is understood. These issues related to inadequate personalised care, a failure to involve carers and recognise their needs, inadequate understanding or curiosity related to personal history and behaviours and an inflexible approach when engagement to services was challenging or difficult for people. These issues had a psychological cost for carers, often centring on role conflict, carer guilt and family conflict (Livingston et al 2010). Clear early assessment of capacity and carer involvement in situations requiring best-interest decisions is an important priority. This can include advance care planning (ACP) and requires further training in facilitating those discussions within the context of dementia (Sampson et al 2005, 2011a, 2011b, Jones et al 2016). This would also seem particularly significant if decision-making could potentially be about complex cancer treatment pathways and the associated risks and side effects that such treatment could entail. The evidence suggests that health professionals find communication challenging in initiating such discussions, particularly around the legal status of ACP, the uncertainty felt by staff and the questionable usefulness of this in relation to dementia (Robinson et al 2012). Making judgements about quality of life becomes more complex and nuanced in the presence of dementia and cancer. Since there is limited evidence of any systematic ACP

decision-making approach in dementia care, it is often left to carers, and this (as with the participants of this study) can mean making complex quality-of-life judgement calls with limited professional support. This is in the context of dementia services being “unpredictable and fragmented” (Denning et al 2012), adding another level of complexity for carers engaged in supporting their care recipient through cancer treatment.

6.4 Concluding remarks

Notions of personhood need to move away from concepts of personhood based on an understanding of autonomy as independence and individualism. For caregivers, respect for personhood is associated with both a value for interdependence and investment in caregiving as a choice. Health professionals need to include carers and not use issues like confidentiality as a blunt instrument to superficially close down communication about complex care issues (as evidenced in the data in this study). It would seem important to acknowledge the ‘multiple voices’ that exist within caregiving relationships and developing strategies in which carers, health professionals and people living with multiple co-morbidities can be meaningfully involved within different complex environments. The narratives of medicine often focus on “restitution” (Frank 1995) in which the clinical drive is to get the patient back to the healthy state prior to a cancer diagnosis. This can be particularly challenging for carers since dementia remains a palliative condition. In response to these findings health professionals need to examine the stigma associated with dementia and reflect on how to communicate effectively with carers. Healthcare professionals within oncology need to create more adaptable treatment pathways that are more responsive to those with cognitive impairment. To tailor this person-centred approach, carers need to be

included within the context of treatment since issues of informed consent, quality of life and person-centred care cannot be adequately explored without the wider inclusion of the network of people who make us who we are.

6.5 Strengths and limitations of the study

I have used COREQ (Tong et al 2007) to examine the strengths and limitations of this study and within domain 1 of the 32 item qualitative checklist (research team and reflexivity) I have had extensive experience and training in conducting qualitative interviewing and have a clinical familiarity with cancer care both within general and specialist roles. I have attempted to present my role in data generation and have explicitly been transparent with interpreting my responses within the data abstracts identified within this thesis in the findings section. This identifies interviewer characteristics and I was explicit at the beginning and throughout the interview of my role as a researcher and nurse to the participants. Within domain 2 (study design) I have used a performative narrative approach and this has been explicitly articulated throughout the methodological chapter and this is reflected in the presentation of the findings and how I have subsequently handled and interpreted these data. The sampling was purposive and snowball and recruitment remained challenging throughout the study. One of the clear limitations is the recruitment through a psycho-oncology department. Whilst this enabled access to the population, the participant's treatment journey could be atypical of carers of people with cancer and dementia and one could argue that those referred to the psycho-oncology service have more established, complex treatment issues than those that were not referred. Most of the sample came from one psych-oncology department at a single cancer centre so again there may be differences between geographical areas based on other factors like service provision to

those people with cancer and dementia. The sample characteristics did not reflect any primary male carers so possible gendered narratives could not be explored within this study. Domain 3 relates to analysis and findings and one of the strengths of this study was my critical supervision, with two academic supervisors examining my case study approach. They explored how I have both positioned myself to the data and how I justified and critically explained the drawing together of some of the common underlying narrative threads from different participants in order to make a coherent argument about carer positioning. This provided rigour in grounding the interpretation within these data and provided further validation.

6.6 Implications for research/practice

The implications for research and practice of these data would suggest that the cancer treatment journey is a significant challenge for carers of people with cancer and dementia. The complexity of the treatment regimes, for example, daily attendance for radiotherapy with movement restrictions related to the actual therapy itself can make issues of compliance an important issue. These pathways appear quite rigid with limited capacity to adapt in meeting the needs of people living with cognitive impairment. This coupled with poor communication between health professionals and carers means those people that know the person with cognitive issues well are often not consulted and excluded from the decision-making process. Early identification of those living with cognitive impairments and a compressive assessment of the support networks that are significant for that person seem an important priority for health professionals. In terms of practice, the involvement of carers (specifically of those who are supporting someone with cancer and dementia) in a

more formalised way to examine, share and advise on the barriers to involvement would seem a foundational requirement in attempting to support this group in navigating care. There may be challenges of carer commitment that could impact on engagement with cancer centres but then it would also require working with organisations like Dementia UK or Alzheimer's Society and using Internet forums and discussion groups to reach and listen to these populations.

The only previous paper that examined carers of people with dementia and cancer is that of Courtier et al (2016). Courtier et al (2016) took a case study design and although they included non-participant observation of carers within their sample population this was restricted to clinical consultations. In terms of building on this research and reflecting on data generated from my study, an ethnographic approach would appear important in mapping the particular points of the cancer treatment journey that may generate particular challenges for carers to navigate. By examining, through non-participant observation, the treatment journey from clinical consultations through to the different treatment therapies a more comprehensive contextual frame can be explored and this could provide a clearer basis for developing future intervention studies based on supporting carer involvement within cancer care. This would also highlight the experiences of people with cognitive impairment in a way that does not primarily focus on memory recall (so often a feature of individual interviewing) and further acknowledges the cultural and environmental factors that can profoundly affect the treatment experience.

6.7 Original contribution to knowledge

This thesis presents the first study specifically examining carers of people living with cancer and dementia. In terms of method, it is the first study involving in-depth interviews and methodologically, the first to use a performative narrative approach in order to analyse these data. The findings highlight the challenges of carers in attempting to navigate cancer treatment and support their relative with dementia. This study therefore provides a foundation to further explore the issues identified, including the complexities of decision-making and how the triad of care (patient/carer/health professional) affect decision-making; how carers could be included throughout the cancer treatment pathways and how health professionals could begin to position carers in ways that maintain and support narrative competence for both themselves and their relative living with dementia.

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Appendices

Appendix 1: Letter of Introduction



Letter of Introduction

I am a researcher involved in the following project:

Memory problems & cancer care: issues related to experiencing & accessing cancer services

The focus of this project will be upon the experiences of accessing and receiving cancer services. We know from the evidence that accessing cancer services can be challenging for people living with memory problems and their carers/supporters. We want to be able to better understand the experiences of carers and people living with memory problems so we can begin to address some of the issues with accessing and receiving cancer services. This project would involve participating in one interview and then keeping either a diary, photo diary, video or audio diary for one week after the interview. The interview will last about 60 minutes in total. The diary is included to try and include other thoughts that you may have reflected on after the interview as finished. If you would like further information about this study please fill in the slip below and give it back to the health professional looking after you. I will then contact you with further information.

I wish to receive further information about this study

☐

I do **not** wish to receive any further information about this study

☐

Name _____

Contact number and/or email address _____

Researcher:

Gary Witham

Senior Lecturer

0161 247 2464

g.witham@mmu.ac.uk

(Please return this form to Jonathan Parker Psycho oncology Department)

Appendix 2: Carer information sheet(s)



Information about the Interview
(carers/relatives)

People living with memory problems & cancer care: issues related to experiencing & accessing cancer services

Introduction

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The focus of this project will be upon the experiences of accessing and receiving cancer services. We know from the evidence that accessing cancer services can be challenging for people living with memory problems and it is an important issue because the chances of having memory problems and cancer increase with age. We know from the evidence that people living with memory problems can experience different health outcomes in cancer treatment when compared with other groups. We want to be able to better understand the experiences of carers and people living with memory problems so we can begin to address some of the problems with accessing and receiving cancer services. We are interested and welcome any views you may have about your experiences, whether these are negative or positive. Any comments you make would be confidential and will not affect your relative/friends care. This project will explore the questions surrounding interactions with health providers and experiences in accessing care.

Why have I been invited?

You have been invited to take part in this research because you have been identified as being involved in supporting someone living with dementia or memory problems who has also been diagnosed with cancer.

Do I have to take part?

It is up to you to decide. This information sheet describes the study and if you wish to take part please complete the consent form. You are free to not take part without giving a reason.

What will I have to do?

I would like you to participate in an interview and then keep either a diary, photo diary, video or audio diary for one week post interview. The interview will last about 60 minutes in total. The topic guide will examine your experiences and the diary will try and include other thoughts that you may have reflected on after the interview as finished.

What are the possible disadvantages and risks of taking part?

There is no foreseeable risk or disadvantage for taking part in this study. If, however, you become distressed whilst taking part in the interview I will take a time out from the interview and the researcher, (who is an experienced health care professional) will offer immediate support. If necessary, with your consent, I would also be able to put you in contact with other health professionals for ongoing support.

What are the possible benefits of taking part?

Whilst there are no direct personal benefits to taking part in this research, it is hoped that this project will lead to demonstrable reasons that if addressed will lead to the improvement in access to cancer services for those people living with memory problems.

What happens when the research study stops?

The data will be examined and used as part of a PhD study. I will also work with The Christie Hospital to highlight the findings, also publish the results in academic journals, and explain the findings at appropriate conferences. I will also send a final report to you.

Will my taking part in the study be kept confidential?

Yes. The interview will be audio-recorded and transcribed. I may use anonymised quotations. All information collected through the interview and diary recordings will be stored securely in a locked cabinet for 10 years. I will follow ethical and legal practice and all information about you will be handled in confidence. All information that is collected through the interview and diaries will be kept strictly anonymous. Any photo diary images of other people will not be used without the written permission of person(s) involved and photographs of children would not be used under any circumstances.

What if there is a problem?

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. If you still wish to pursue your concerns further, participants should write or email the following person:-

Professor Juliet Goldbart
Director, Research Institute for Health and Social Change
Manchester Metropolitan University
Hathersage Road
Manchester, UK
M13 0JA

+44 (0)161 247 2563
Fax: +44 (0)161 247 6842
j.goldbart@mmu.ac.uk

Harm

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for legal action for compensation against the Manchester Metropolitan University but you may have to pay your legal costs.

Who is organising and funding the research?

This work is part of a PhD study with Manchester Metropolitan University.

Who has reviewed the study?

All research in the University is looked at by independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the University Research Ethics Committee.

You should retain this information Leaflet.

Further information and contact details.

If you require further information regarding:

1. General Information about the research
2. Specific information about the research project.

3. Advise as to whether you should participate.
4. Who you should approach if unhappy with the study.

Please contact

Gary Witham: Senior Lecturer

Manchester Metropolitan University

g.witham@mmu.ac.uk

0161 247 2464

Appendix 3 information sheet

(For external to NHS)



Information about the Interview

(carers/relatives)

People living with memory problems & cancer care: issues related to experiencing & accessing cancer services

Introduction

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The focus of this project will be upon the experiences of accessing and receiving cancer services. We know from the evidence that accessing cancer services can be challenging for people living with memory problems and it is an important issue because the chances of having memory problems and cancer increase with age. We know from the evidence that people living with memory problems can experience different health outcomes in cancer treatment when compared with other groups. We want to be able to better understand the experiences of carers and people living with memory problems so we can begin to address some of the problems with accessing and receiving cancer services. We are interested and welcome any views you may have about your experiences, whether these are negative or positive. Any comments you make would be confidential and will not affect your relative/friends care. This project will explore the questions surrounding interactions with health providers and experiences in accessing care.

Why have I been invited?

You have been invited to take part in this research because you have been identified as being involved in supporting someone living with dementia or memory problems who has also been diagnosed with cancer.

Do I have to take part?

It is up to you to decide. This information sheet describes the study and if you wish to take part please complete the consent form. You are free to not take part without giving a reason.

What will I have to do?

I would like you to participate in an interview and then keep either a diary, photo diary, video or audio diary for one week post interview. The interview will last about 60 minutes in total. The topic guide will examine your experiences and the diary will try and include other thoughts that you may have reflected on after the interview as finished.

What are the possible disadvantages and risks of taking part?

There is no foreseeable risk or disadvantage for taking part in this study. If, however, you become distressed whilst taking part in the interview I will take a time out from the interview and the researcher, (who is an experienced health care professional) will offer immediate support. If necessary, with your consent, I would also be able to put you in contact with other health professionals for ongoing support.

What are the possible benefits of taking part?

Whilst there are no direct personal benefits to taking part in this research, it is hoped that this project will lead to demonstrable reasons that if addressed will lead to the improvement in access to cancer services for those people living with memory problems.

What happens when the research study stops?

The data will be examined and used as part of a PhD study. I will also publish the results in academic journals, and explain the findings at appropriate conferences. I will also send a final report to you.

Will my taking part in the study be kept confidential?

Yes. The interview will be audio-recorded and transcribed. I may use anonymised quotations. All information collected through the interview and diary recordings will be stored securely in a locked cabinet for 10 years. I will follow ethical and legal practice and all information about you will be handled in confidence. All information that is collected through the interview and diaries will be kept strictly anonymous. Any photo diary images of other people will not be used without the written permission of person(s) involved and photographs of children would not be used under any circumstances.

What if there is a problem?

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. If you still wish to pursue your concerns further, participants should write or email the following person:-

Professor Juliet Goldbart
Director, Research Institute for Health and Social Change
Manchester Metropolitan University
Birley Building

Birley Fields Campus

53 Bonsall Street

Manchester

M15 6GX
+44 (0)161 247 2563
Fax: +44 (0)161 247 6842
j.goldbart@mmu.ac.uk

Harm

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for legal action for compensation against the Manchester Metropolitan University but you may have to pay your legal costs.

Who is organising and funding the research?

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You should retain this information Leaflet.

Further information and contact details.

If you require further information regarding:

5. General Information about the research
6. Specific information about the research project.
7. Advise as to whether you should participate.
8. Who you should approach if unhappy with the study.

Please contact

Gary Witham: Senior Lecturer

Manchester Metropolitan University

g.witham@mmu.ac.uk

0161 247 2464



Appendix 4: Consent form(s)

CONSENT FORM

Title of Project: **People living with memory problems & cancer care: issues related to experiencing & accessing cancer services**

Name of Researcher: G Witham

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

3. I agree to the interview being audio recorded and transcribed.

☐

4. I agree to the use of anonymised quotes in publications.

☐

5. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person	Date	

Appendix 5: Interview guide



Interview guide

What are your experiences of accessing treatment?

What are your experiences of interactions with health care professionals?

If there were problems, what were they?

What could have been done that would be more helpful in accessing treatment for yourself or your relative/friend/partner?

How can health professionals better support you better throughout treatment for yourself or your relative/friend/partner?

Appendix 6: NHS Ethical Approval/MMU



Health Research Authority
NRES Committee North West - Greater Manchester South
HRA NRES Centre Manchester
3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7830

07 January 2014

Mr Gary Witham
Senior Lecturer
Manchester Metropolitan University
Elizabeth Gaskell Campus
Hathersage Road
Manchester
M13 0JA

Dear Mr Witham,

Study title:	Dementia & Cancer care: issues related to experiencing & accessing cancer services
REC reference:	13/NW/0717
Protocol number:	N/A
IRAS project ID:	131992

Thank you for your letter responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Acting REC Manager Miss Nicola Burgess, nrescommittee.northwest-gmsouth@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

The committee did not approve this research project for the purposes of the Mental Capacity Act

The Research and Development Division



Holly White: R&D Coordinator
Lifen Wang: Research Governance and Information Manager
The Research and Development Office
The Christie NHS Foundation Trust
Block C, Withington Hall
Wilmslow Road
Withington
Manchester M20 4BX
Tel: 0161 446 3985
Fax: 0161 446 8201
e-mail: lifen.wang@christie.nhs.uk
e-mail: holly.white@christie.nhs.uk

Mr G Witham
Nursing Admin.
The Christie NHS Foundation Trust
Wilmslow Road
Withington
Manchester

24 January 2014

Dear Mr Witham

ID: 13_SERVICE_27PI Dementia & cancer care: issues related to accessing and experiencing cancer services

Re: NHS Permission for Research – Participant Identification Centre (PIC) only

EudraCT no: n/a (non-CTJMP)
Ethics reference: 13/NW/0717
IRAS/CSP reference: n/a (non-CSP)

Thank you for providing the Research & Development (R&D) office with your study information.

The above study was considered by the R&D office, where based on the information provided the impact of the study on the Trust's resources was reviewed. The review was carried out in line with the Research Governance Framework. I am now happy to authorise NHS permission for The Christie NHS Foundation Trust on the understanding that the permission for The Christie site is for Research Participant Identification activity only. Following the review, NHS permission has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Protocol version 2.0, dated 29 November 2013
Letter of invitation to participant version 1.0, dated 02 September 2013
Participant Information Sheet: Person living with memory problems version 2.0, dated 29 November 2013
Participant Information Sheet: Information about the interview (carers/relatives) version 2.0, dated 09 December 2013
Participant Information Sheet: For participants living with memory problems version 2.0, dated 09 December 2013
Interview Guide version 1.0, dated 02 September 2013
REC application form 131992/508702/1/747
Ethics approval letter dated 07 January 2014

Yours sincerely

Appendix 7: Manchester Metropolitan University Ethical Approval

MANCHESTER METROPOLITAN UNIVERSITY
FACULTY OF HEALTH, PSYCHOLOGY AND SOCIAL CARE

M E M O R A N D U M

FACULTY ACADEMIC ETHICS COMMITTEE



To: Gary Witham

From: Prof Carol Haigh

Date: 13/01/2014

Subject: Ethics Application 1206

Title: Dementia & cancer care: issues related to experiencing & accessing cancer services

Thank you for your application for ethical approval.

The Faculty Academic Ethics Committee review process has recommended approval of your ethics application. This approval is granted for 42 months for full-time students or staff and 60 months for part-time students. Extensions to the approval period can be requested.

If your research changes you might need to seek ethical approval for the amendments. Please request an amendment form.

We wish you every success with your project.

A handwritten signature in black ink, appearing to be "Carol Haigh".

Prof Carol Haigh and Prof Jois Stansfield
Chair and Deputy Chair
Faculty Academic Ethics Committee

MANCHESTER METROPOLITAN UNIVERSITY
FACULTY OF HEALTH, PSYCHOLOGY AND SOCIAL CARE

M E M O R A N D U M

FACULTY ACADEMIC ETHICS COMMITTEE



To: Gary Witham

From: Prof Carol Haigh

Date: 11/09/2014

Subject: Amendment to Ethics Application 1206

Title: Dementia & cancer care: issues related to experiencing & accessing cancer services

Thank you for your application for an amendment to your original ethical approval.

The Faculty Academic Ethics Committee review process has recommended approval of your amendment. This approval is granted for 42 months for full-time students or staff and 60 months for part-time students. Extensions to the approval period can be requested.

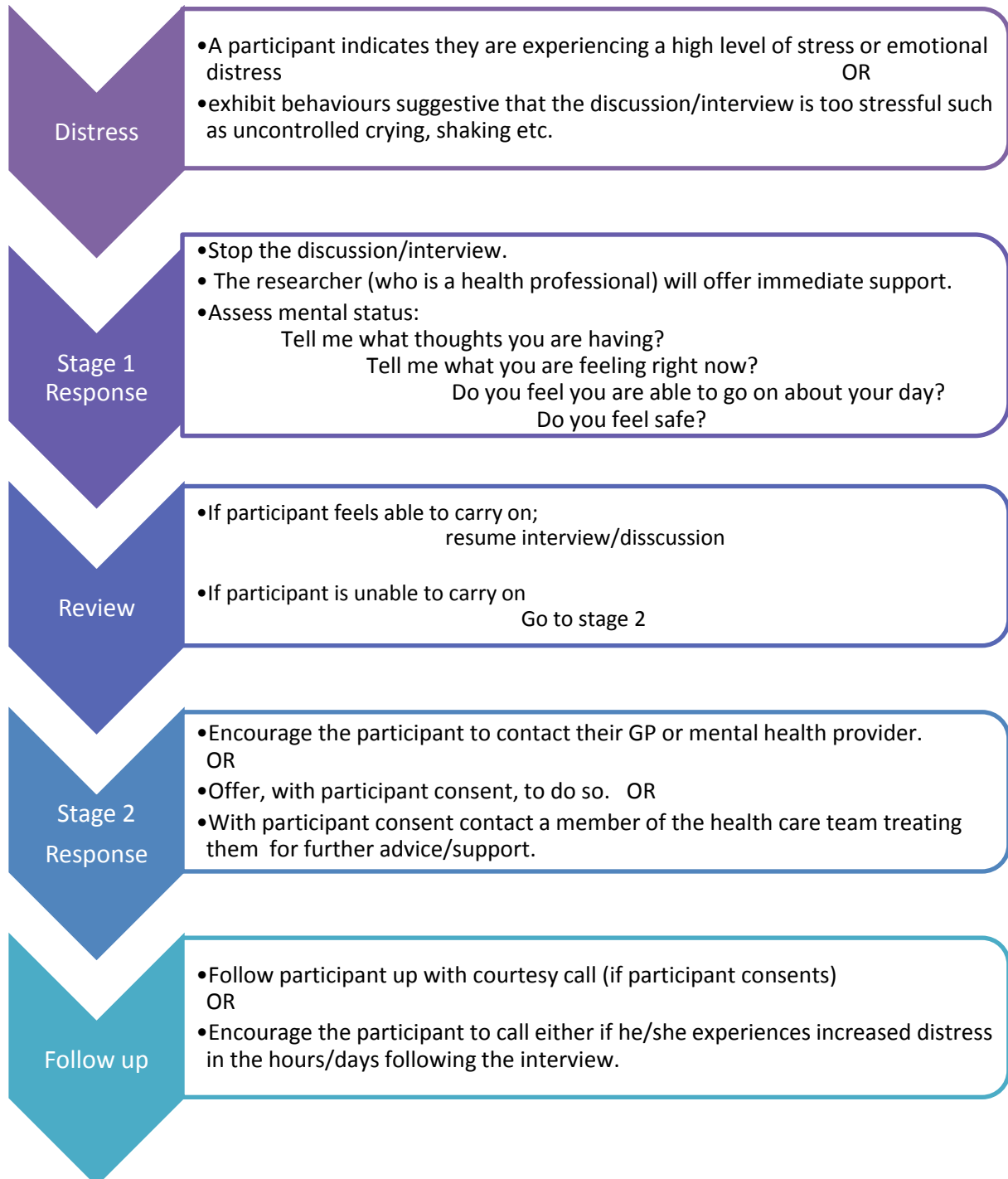
If your research changes you might need to seek ethical approval for the amendments.
Please request an amendment form.

We wish you every success with your project.

Prof Carol Haigh and Prof Jois Stansfield
Chair and Deputy Chair
Faculty Academic Ethics Committee

Appendix 7: Distress Policy

The protocol for managing distress in the context of a research interview



Modified from : Draucker C B, Martsof D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics. *Archives of Psychiatric Nursing* 23 (5) pp 343-350

Gary Witham/Carol Haigh Feb 2011

Appendix 8: Relevant peer reviewed publications/conference presentations

Witham G, Haigh C, Mitchell D, Beddow C (2017) Carer experience supporting someone with dementia and cancer: a narrative approach, *Qualitative Health Research*,
<https://doi.org/10.1177/1049732317736285>

2015: International Conference on Cancer Nursing (ICCN) Vancouver, Canada, July 8-11th

Oral presentation : The Informal carer experience of supporting someone living with dementia undergoing cancer treatment.

2016: Christie NHS Foundational Trust Study day: 14th April 2016 “Older People, Cancer and Dementia: Current Issues & Innovations”, Oral presentation: The Informal carer experience of supporting someone living with dementia undergoing cancer treatment.